The Development of a New Theoretical Framework to Explore Type 2 Diabetes Self-Management Behaviours in UK South Asian Patients: Recommendations for Healthcare Practice.

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Abstract

Type 2 diabetes (T2D) is a significant public health concern with a high prevalence within the UK South Asian (SA) population. T2D is predominantly managed by lifestyle behaviours such as diet, exercise, medication and self-monitoring of blood glucose. Previous research has highlighted that SA people's self-management behaviours might be influenced by cultural and religious influences that in turn may explain substandard clinical T2D outcomes in this group. However, it is not clear how cultural and religious factors act on such self-management behaviours. Previous research has not explored how to specifically help SA people create sense, meaning or how to acknowledge such cultural and religious influences relevant to their T2D management. This PhD aimed to understand self-management behaviours of SA individuals with T2D.

This PhD thesis presents a number of studies which each explore specific aspects of the influences of T2D self-management in the SA population. New evidence has been created through the completion of a meta-synthesis, which reconstructed and reanalysed previous literature on SA patients' self-management behaviours. In addition, three qualitative Grounded Theory (GT) studies explored multiple perspectives of those involved with T2D care for the SA population: this included one study with health professionals working in T2D care, a second study conducted with SA patients diagnosed with T2D, and a third study which explored family members perspectives of living with and supporting another SA family member with T2D. Each study offers unique contributions to the evidence-base and creates new knowledge, to develop a thorough and comprehensive understanding of the overall PhD aim. The individual GT studies and the meta-synthesis were integrated to produce a higher-order Grounded Formal Theory (GFT). A subsequent validation study was completed to ratify the development of the GFT. Utilising the GFT and validation study, the final study describes the development of a training intervention which utilised participatory research processes and aimed to implement the new evidence-based GFT into an applied setting with the objective of improving health professional T2D communication and care practices.

The findings of this PhD explore a range of psychological and behavioural variables relevant to each study, to the final GFT, and these were subsequently used in the development of a health professional intervention. The PhD findings are discussed with relevance to previous literature and specific contributions to new knowledge. Overall, diabetes self-management in SA's is influenced by multiple factors, including health professional interactions and the perceived relevance of advice received; the patient's psychological understanding, alongside their acceptance of, T2D as part of their identity; and their family's role in supporting their decisions for implementing healthcare advice. The findings are discussed with reference to psychological theories. In addition, this PhD necessitates a holistic approach to understanding self-management in the SA community, and the findings have been fully integrated to present a GFT to explain SA T2D self-management behaviours fully. Furthermore, aspects of the GFT have been developed further and have informed a practice-based health professional training intervention, to help health professionals understand SA patients' perspectives of T2D, which recognise social-cultural influences on behavioural decisions.

Strengths and weakness of the PhD are acknowledged, and the relevance of this research to the real world applied T2D settings is highlighted, alongside a call for further research to develop this research further.

Publications/ Oral presentations/ Posters

Oral presentations

Patel, T. & Newson, L. M. Reducing health professional and patient conflict in consultations; working together to prevent complications. INVITED SPEAKER. 10th World Congress of Diabetes and its Complications. Edinburgh, UK 15th-18th July 2018.

Newson, L. M., **Patel. T.,** Poole, H., Umeh, F. Diabetes management of South Asian people in the UK. Integrating a patient’s psychology into diabetes care: A truly patient centred care approach. INVITED SPEAKER. Diabetes UK, London 2018.

Patel, T. & Newson, L. M. Health professional’s cultural competency: Delivering diabetes care to South Asian patients. INVITED SPEAKER. Diabetes UK, London 2018.

Patel, T., Newson, L., Umeh, F K., & Poole H. Investigating health professional's experiences of South Asian patient's adherence to self-management with Type 2 diabetes. EHPS/DHP 2016, 23-27 Aug 2016. Oral Presentation.

Patel, T., Newson, L., Umeh, F K., & Poole H. Investigating health professional's experiences of South Asian patient's adherence to self-management with Type 2 diabetes. LJMU Postgraduate conference, June 2015, Liverpool, UK. Oral Presentation.

Posters

Patel, T., Newson, L., Kanayo, U., & Poole, H**.** Investigating the needs and experiences of South Asian patients with Type 2 Diabetes. A Grounded Theory approach exploring culture, religion, and the role of family members. Poster presented at Diabetes UK, March 2017, Manchester, UK. https://doi.org/10.1111/dme.13302

Newson, L. M., **Patel. T.,** Poole, H., Umeh, F. A participatory action research intervention to support health professionals improve communication with South Asian patients with type 2 diabetes. Poster presented at Diabetes UK, March 2017, Manchester, UK. https://doi.org/10.1111/dme.13302

Patel, T., Newson, L., Umeh, K., & Poole, H. (2014). A qualitative meta-synthesis: Adherence to Type 2 diabetes treatment regimes within the UK South-Asian population. Poster presented at South Asian Health Foundation conference, October 2014, Birmingham, UK.

Patel, T., Newson, L., Umeh, K., & Poole, H. (2014). A qualitative meta-synthesis: Adherence to Type 2 diabetes treatment regimes within the UK South-Asian population. Poster presented at LJMU Postgraduate conference, 18th June 2014, Liverpool, UK.

Patel, T., Newson, L., Umeh, U., & Poole, H. (2014) Looking into the future! Poster presented at LJMU Teaching and Learning Conference, 17th June 2014, Liverpool UK.

Dedication

This thesis is dedicated to my parents, Iqbal & Saeeda, and grandparents, Dada & Dadi; Nona & Noni.

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I wish to express my appreciation to my colleague and friend Sharon, who started this journey, and we will now finish the journey together, thank-you for always being there for me through the ups and the downs. My fellow PhD colleagues and friends Alex, Connor, Ben and Ishfaq for your continuous support.

A thank-you to my family, my grandparents, I would not be here without your duas, my parents, I could not have got this far way without your support. My siblings for supporting me through this journey, I appreciated everything you have done for me and, also my nieces, Malaika, Mehzabeen, Maeesha, Maleehah, Muzaynaah, Maariyah, Maryam, Ayesha and Aminah, and nephews, Ibrahim and Umar, for always being amazing little humans.

Finally, to my husband, Arif, you have been through it all with me, the ups and the downs. Thank you for the continuous support, love, guidance and listening ear you have provided throughout this journey.

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List of abbreviations

T2D - *Type 2 diabetes*

SA - *South Asian*

PA - *Physical Activity*

SMBG - *Self-Monitoring of Blood Glucose*

GT - *Grounded Theory*

CIS - *Critical Interpretive Synthesis*

UK - *United Kingdom*

ONS - *Office of National Statistics*

WHO - *World Health Organisation*

IDF - *International Diabetes Federation*

NICE - *National Institute for Health and Care Excellence*

HBM - *Health Belief Model*

TTM - *Trans-Theoretical Model*

PMT - *Protection Motivation Theory*

TPB - *Theory of Planned Behaviour*

SES - *Socio- Economic Status*

CQC - *Care Quality Commissioner*

GPs - *General Practitioner*

DSN - *Diabetes Specialist Nurse*

GFT - *Grounded Formal Theory*

PPI - *Patient Public Involvement*

CPD - *Continuous Professional Development*

Research Team

Tasneem Patel (Researcher)

A postgraduate researcher and Trainee Health Psychologist with research interests in long-term conditions and Black and Minority Ethnic groups.

Dr Lisa Newson (Director of Studies (DoS))

An HCPC registered and chartered Health Psychologist with applied diabetes research experience and a portfolio of qualitative research expertise.

Dr Kanayo Umeh (Supervisor)

A Chartered Psychologist with an interest in bio-psych-social interactions of diabetes research

Dr Helen Poole (Supervisor)

A Reader in Applied Health Psychology and HCPC registered Health Psychologist with a range of research expertise across both qualitative and quantitative methods and long-term conditions.

Throughout this thesis, the term ‘research team’ will refer to the above.

PhD Overview

This PhD reviews and explores self-management behaviours in patients with Type 2 diabetes (T2D), who live in the UK and from a South Asian (SA) descent, with a view to developing a comprehensive theoretical understanding of the topic and using this new evidence-base to develop and feasibility test a new intervention to improve diabetes self-management.

Thesis structure

This thesis presents the following key chapters which each contribute to new evidence: 1) a systematic meta-synthesis; 2) three qualitative studies exploring a) health professionals, b) patients c) family and friend’s experiences and perceptions of T2D; 3) the development and validation of a Grounded Formal Theory (GFT) and 4) the development and delivery of a pilot intervention. This thesis has been organised into Parts A-D:

Part A

Chapter 1: Introduction
Chapter 2: Literature Review
Chapter 3: Systematic Synthesis of Qualitative Research

Chapter 1: Provides an introduction to the SA population group, and a brief overview of T2D and its prevalence in this cohort. This chapter provides justification as to why this is an important topic to investigate.

Chapter 2: Reviews the previous evidence-base on adherence to self-management in the SA population. This review is used to inform the subsequent meta-synthesis and highlights the gap in the current research literature.

Chapter 3: A Critical Interpretative Synthesis (CIS) (a type of meta-synthesis) was completed to bring together the previous qualitative evidence base and inform the direction of this PhD research, highlighting gaps in the current evidence base. The CIS was conducted to explore how a patient's cultural identity influences their self-management behaviours.

Unique Contribution to Knowledge:
This PhD presents the first CIS conducted to connect, deconstruct and re-contextualise findings of previous literature. This analysis has presented a new theoretical framework: When SA patients experience internal conflict e.g. between their T2D; their daily lifestyle/roles which influence their behaviour; and their doctor patient relationships conflicts exist between their beliefs and implementation decisions. Consequently, individuals have to, somehow, resolve this conflict, often patients prioritised cultural influences on their lifestyle behaviours before implementing the recommended T2D self-management behaviours.

Part B
Chapter 4: Methodology
Chapter 5: Study 1
Chapter 6: Study 2
Chapter 7: Study 3

Chapter 4: This chapter explored the different qualitative methodologies and approaches, followed by an explanation towards the orientation of this research process. The lead researcher is positioned as an interpretivist researcher. A detailed account of Grounded Theory (GT) methodology and analysis as applied throughout this research thesis is also presented.

Chapter 5: *Study 1* – Qualitative study investigating health professionals perceptions and experiences of supporting diabetes self-management in SA patients.

Chapter 6: *Study 2* – Qualitative study exploring cultural factors in diabetes self-management amongst SA patients.

Chapter 7: *Study 3* – Qualitative study exploring the experience, attitudes and views of a family member or friend involved in the care of SA patients with T2D.

Chapter 5: Study 1- Unique contribution to knowledge:
The findings highlighted health professional lack understanding of SA population patient needs, which influences their delivery of care, presenting a weakened patient-care approach. This GT study highlights how health professional's own ethnicity influenced their delivery of care, it is noteworthy that previous studies have not considered this as relevant to the analytical process.

Chapter 6: *Study 2* – Unique contribution to knowledge:
The SA population are a heterogeneous group, and as such, their beliefs, attitudes and experiences differ and vary relevant to their cultural identity. Their individual health beliefs more specifically, religious diversity of SA patients, was a revelatory finding which needs to be considered as an important part of understanding patients' person-centred care needs.

Chapter 7: *Study 3* – Unique contribution to knowledge:
This study highlights that the SA family members influence diabetes self-management behaviours, however, it is complex as the support can vary in terms of emotional and practical support as different relationships play different roles i.e. (wife provides emotional support and the daughter was found to provide practical support). However, it is noteworthy that although current guidelines recommend family members to be involved in patient care, this study highlighted that there is lack of resources and support to allow family members to help patients engage with diabetes self-management behaviours.

Part C

Chapter 8: *A summary of the three previous qualitative studies and general discussion which are integrated into the development of a Grounded Formal Theory (GFT)*

Chapter 9: Study 4: GFT Validation

Chapter 10: Study 5: Development and delivery of a pilot intervention and evaluation

Unique contribution to knowledge:

This section presents a new GFT based on the integration of evidence across the three previous qualitative studies, this is unique in that previous research has not considered this topic from such a comprehensive variety of perspectives, and the discussion of the GFT is explored through consideration of psychological variables which influence T2D self-management behaviour. GFT is the first to have fully integrated empirical research from multiple studies to present a holistic understanding of SA patient's T2D self-management behaviours. The GFT brings together multiple perspectives, and explanations for the complexity of self-management behaviours are offered through the entwining of multiple psychological theories. The GFT highlights that individual behaviour change theories are in part relevant, although the GFT extends this understanding, to consider social-cultural and environmental contexts of self-management behaviour.

The validation study helps to consider the transfer of evidence-based practice (new empirical research), into practice-based evidence, so that the new theoretical knowledge presented can be implemented into clinical practice.

The focus of the development of a pilot training intervention was uniquely informed by the GFT evidence-based and designed around the core constructs of cultural identity, person centred-care and health communication practices. The process of intervention development was also taken through a participatory research process to ensure real-world relevance, so that health professionals could make use and implement the

Part D

Chapter 11: Overall Discussion and PhD conclusion

Chapter 11: This chapter explores the overall findings of the PhD thesis to answer the original research question.
The discussion focuses on the theoretical and conceptual frameworks previously presented and explores the relevance of other psychological theories and previous evidence. The discussion chapter outlines the contribution to new knowledge, the potential to impact and highlights the role of disseminating the research. Strengths and limitation of the PhD are highlighted.

Overall Unique contribution to knowledge:
Health professionals have a poor understanding of cultural and religious issues affecting diabetes self-management in SA.

Patients play an important role in their own self-management, and may experience conflict between their culture and the demands of diabetes self-management
Family members have a major influence on self-management on everyday lives of people with diabetes.
The overall unique contribution of this thesis is the development of a new theoretical framework which informs to change communication in practice, by delivering information focussing on the patient.

Part A

Chapter 1 – An introduction chapter with an overview of the SA population group and a description of T2D self-management behaviours.

Chapter 2 – A review of the previous evidence-base on adherence to self-management behaviours in the SA population.

Chapter 3 – A systematic review and meta-synthesis relating to T2D self-management behaviours within the UK SA population.

Chapter 1: Introduction

Introduction – Chapter overview

This chapter introduces the concepts of ethnicity, culture and religion specific to the South Asian (SA) population and the complex nature of these terms. A brief overview of Type 2 diabetes (T2D) is provided and considered with relevance to the growing prevalence to the United Kingdom (UK) SA population. Finally, this chapter provides an overview of how health psychology has informed this thesis.

1.1. Ethnicity – Definition

> *‘In principle, an ethnic group would be defined as a community whose heritage offers important characteristics in common between its members and which makes them distinct from other communities. There is a boundary, which separates ‘us’ from ‘them’, and the distinction would probably be recognised on both sides of that boundary. Ethnicity is a multi-faceted phenomenon based on physical appearance, subjective identification, cultural and religious affiliation, stereotyping, and social exclusion. But it is not possible in advance to prescribe what the key distinguishing characteristics might be; the components of ethnicity will be different in Britain compared with, say Northern Ireland, Belgium, Bosnia, the United States, Rwanda, India or Singapore. So it is necessary to adopt a flexible and practical approach to choosing the specific criteria to identify the important ethnic boundaries in any particular society’* (Modood, Lakey, Nazroo, Smith, Virdee, Beishon, 1997, p. 13).

Ethnic differences are often used to explain inequalities (Darlington, Norman, Ballas, & Exeter, 2015). In 1960, the UK population consisted of 52.2 million people, by 2017 the population increased to 65.38 million and projected to increase to 84.5 million by 2061. It is estimated that ethnic groups will make up 30% of the UK population by 2061 (Rees, Wohland, Norman, Lomax, & Clark, 2017). It is noteworthy that the census only included ethnicity as a recorded category from 1991 (Ballard, 1996; Sillitoe & White, 1992).

1.2. Ethnic composition in the UK

SA migration in the UK is complex. People of SA origin have come from different social and economic backgrounds, have different migration journeys and have varied reasons for settling in the UK. The partitioning of India in 1947 constituted two independent states, India and Pakistan, and then later on the emergence of Bangladesh (in 1971, following the civil war between East and West Pakistan) (*Figure 1.1*). The eruption of violence and conflict prior to, and post-partition (Kaul, 2001), encouraged large numbers of people to migrate across Europe, the United States, Canada and other parts of the world.

Figure 1.1: Partitioning of India 1947, adapted from BBC NEWS., retrieved January 2017, from http://news.bbc.co.uk/1/hi/in_depth/629/629/6922293.stm.

In Britain, due to both the partition conflicts and labour shortages, there was an influx of Indian, Pakistani and Bangladeshi migrants from the late 1960s, through to 1980’s (Ballard, 2003; Nazroo & Williams, 2005). Initially, single males came to work in the UK and sent money back to their families in their respective native country. Following the implementation of the Commonwealth Immigrants Act (1962), which restricted the free movement of work, immigrants at this time chose to return to their native country or remain and re-build their family unit in the UK.

As a result of this migration, there was a significant growth of ethnic minority population in the UK (Peach, 1997). Large cities were selected for residence with the Bangladeshi population clustering the London Borough of Tower Hamlets; Pakistanis in London, Birmingham, Manchester, Bradford, Leeds and Luton. With the Indian population, being very diverse in religions, the Sikhs predominantly located in London, Birmingham and Wolverhampton; and Hindus in London and Leicester (Finney & Jivraj, 2013). Today, the UK is one of the countries that make up a significant and growing portion of SA migrant population, which include diverse cultures and communities (Hanif & Karamat, 2009). With the ethnic diversity that exists, it is noteworthy that a number of languages and dialects are associated to the SA sub-groups (for example, Gujarati, Hindi, Urdu, Punjabi, Bengali, and Sylheti), which can be difficult to measure (Senior & Bhopal, 1994) consequently, it is useful to explore the vast needs to establish and help inform health policies appropriately.

There are various categorisations for the term “Asian”, depending on the originating country where the published work has been conducted. For example, in Canada, the term SA is grouped Bangladeshi, Bengali, East Indian, Goan, Gujarati, Kashmiri, Pakistani, Punjabi, Nepali, Sinhalese, Sri Lankan and Tamil (Statistics Canada, 2007). In the UK, the ethnic category ‘Asian’ is used only to refer to people originating from the Indian subcontinents’ Pakistan, India, Bangladesh and Sri Lanka, and a small proportion from East Africa, Kenya, Tanzania and Uganda (Aspinall, 2003; Bhopal, Phillimore, & Kohli, 1991; Office of National Statistics (ONS), 2012).

However, the census only reports Pakistani, Indian and Bangladeshi population statistics (ONS, 2012) (*Figure 1.2*).

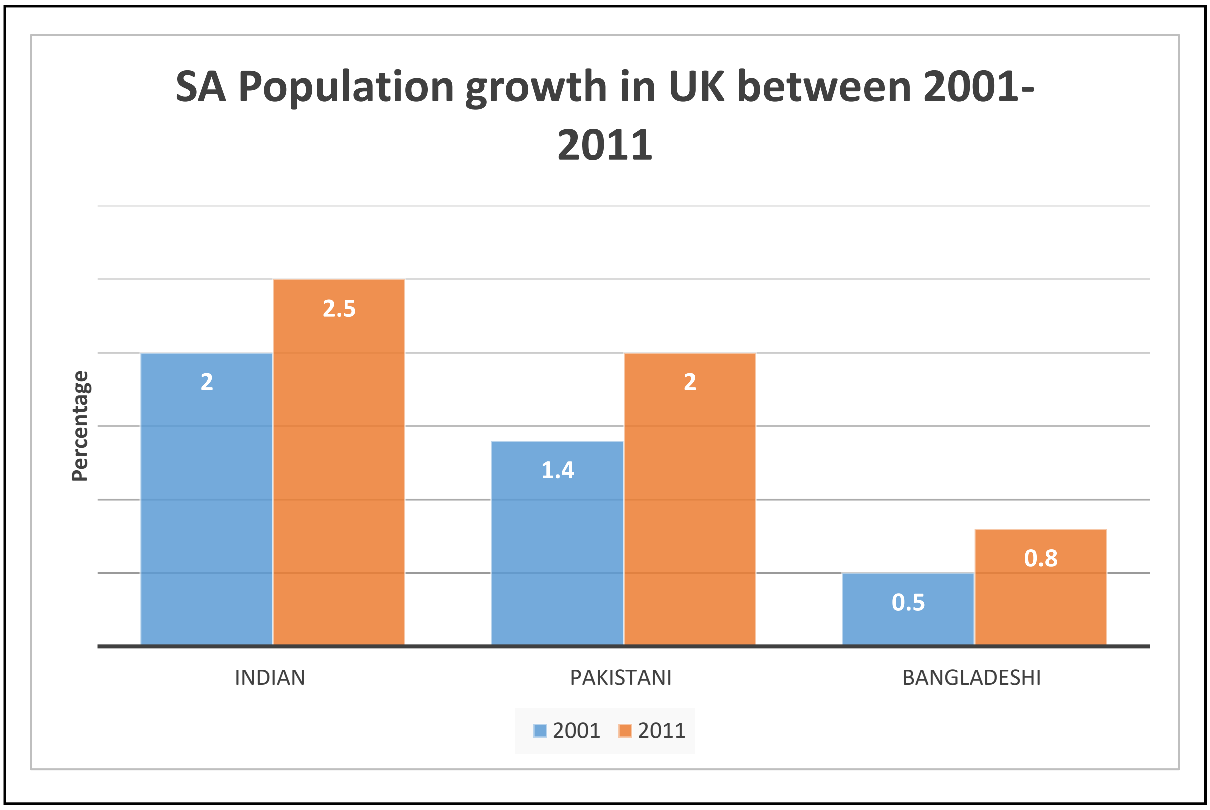

Figure 1.2: Census data - Growth of SA population 2001 and 2011

1.2.1. Culture

According to Spencer-Oatey (2008) ‘Culture is a fuzzy set of basic assumptions and values, orientations to life, beliefs, policies, procedures and behavioural conventions that are shared by a group of people, and that influence (but do not determine) each member’s behaviour and his/her interpretations of the ‘meaning’ of other people’s behaviour’ (p.3). In the context of the SA population, cultural practices are specific and important to this population (Dwyer, 2000). For example, specific to health outcomes;

women are seen to be the person who looks after the household and takes on the responsibilities for all chores, as that is what is expected of them culturally, which may restrict their opportunities to make time for themselves (Choudhry, 2001).

1.2.2. Diversity – Religion, ethnicity and culture

SA’s are ethnically diverse and often characterised by their religious status (Peach, 2006). Individuals identify themselves via a religious label. According to the 2011 census, the three most prominent religions in the UK SA’s were Hinduism, Islam and Sikhism (O'Brien & Potter-Collins, 2015) (*Figure 1.3*). However, an individual’s actual identity is multifaceted (Bell, 2016) and not merely defined by a religious label. Moreover, nuances exist within religious affiliations. While individuals may affiliate themselves to a specific religion, nuances in how they engage and apply religious influences exist. For example, some individuals are ‘actively’ practising religion, whereas others may not consider themselves as practising religious teachings (e.g. for a Muslim individual attending to five times daily prayers is a compulsory obligation that is adhered too). Individuals are therefore defined by a mixture of religious, ethnic and cultural interpretations, which influence personal beliefs and behaviours. For example, a SA Muslim may engage in Ramadan and Eid (religious festivals), culturally they may participate in Muslim social events and activities. However, they may also choose (known or unknown to family members/religious community) also engage in Western lifestyle behaviours (such as consuming alcohol), which are not considered acceptable religious behaviours (Valentine, Holloway, & Jayne, 2010). However, engaging in such behaviours, do not detract from their identification of being SA Muslim (for example, attending Friday prayers, Jumah) where it is an opportunity for Muslims to congregate together and receive a sermon (Bowen, 1989). The diversity which exists across SA individuals means that beliefs, attitudes, and engagement in lifestyle behaviours vary considerably across SA individuals. Thus, the SA population should be considered a highly heterogeneous population group. Simply defining individuals as SA may not be helpful in understanding their needs.

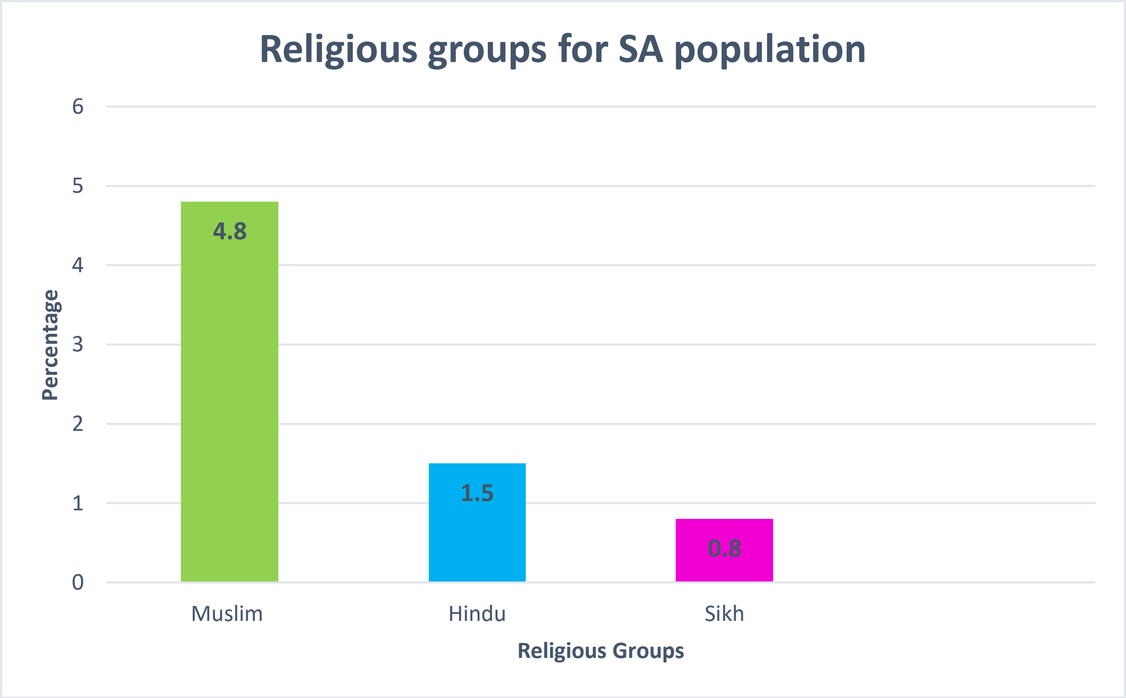

Figure 1.3: Census data- Religious group for SA population

1.3. North-West England

The North-West of England is one of the several areas of SA population concentration (ONS, 2012). Specifically, there is a high SA population residing in Bolton, Blackburn and Preston (*Figure 1.4*). This PhD focuses on Pakistani, Indian and Bangladeshi SA population representing the SA population within the North-west of England, where this research has been conducted.

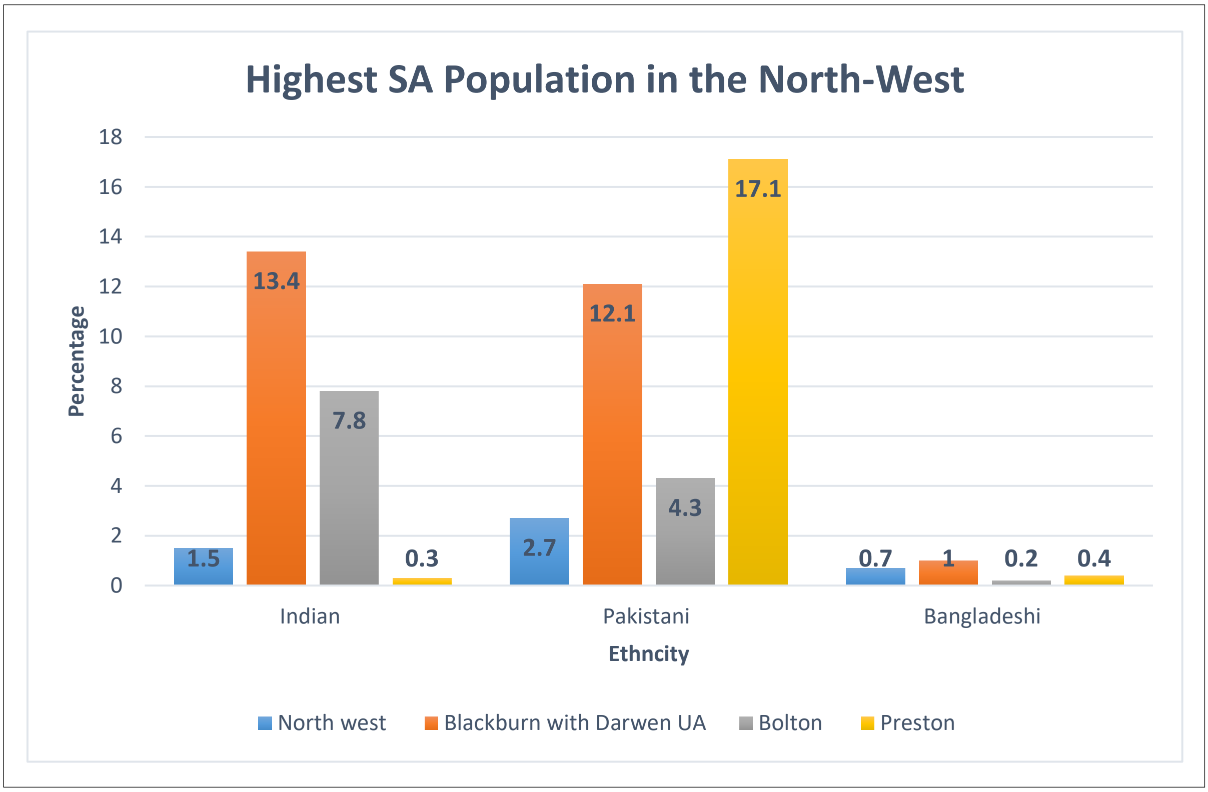

Figure 1.4: SA population in North West

The North-west of England has higher rates of deprivation than the national average (The English Indices of Deprivation, 2015). In addition, the prevalence of specific health conditions, such as diabetes, are higher than the national average (Quality and Outcomes Framework, 2016-17), and diabetes hospitalisation is higher (Hospital Admitted Patient Care Activity, 2016-17).

1.4. Diabetes

Diabetes Mellitus is a condition that is characterised by continued hyperglycaemia, which causes a shortage in the release of insulin and can cause long-term complications and failure of numerous organs (World Health Organisation, (WHO), 2016). In T2D, the body builds up resistance to insulin, so more insulin is needed to bring down blood glucose levels (insufficient secretion of insulin from the β-cells of the pancreatic islets), and together people with T2D experience impaired insulin action that targets tissues such as muscle, liver and fat (a condition termed insulin resistance) meaning the body no longer uses insulin well. It can also mean that the pancreas is still producing insulin as it should, but it is just not enough (Butler, Janson, Bonner-Weir, Ritzel, Rizza, & Butler, 2003; Lebovitz & Banerji, 2004; Saltiel & Olefsky, 1996). At present, there is no cure for diabetes, treatment involves lifestyle changes and by adopting self-management behaviours to treatment has been found to predict and improve both symptoms and outcomes (von Arx, Gydesen, & Skovlund, 2016).

T2D is recognised as one of the most common health disorders in the UK and is becoming a global health concern (Dorajoo & Boehm, 2015; Seuring, Archangelidi, & Suhrcke, 2015; Qi, Wang, Strizich, & Wang, 2015; WHO, 2016; Wu, Ding, Tanaka, Zhang, & Risk, 2015). In 2017, the International Diabetes Federation (IDF) reported that that the prevalence of diabetes was 8.8% worldwide and the estimated prevalence is predicted to increase to 9.9% by 2045 (IDF, 2018), and to affect one in ten people by 2040 (WHO, 2016). According to the NHS Digital (2017), there are 2,721,580 people registered with T2D in England and Wales, this is an increase of 20.2% in only one year, from 2,263,484 recorded the previous year.

The prevalence of T2D is increasing in the UK SA community (Gujral, Pradeepa, Weber, Narayan, & Mohan, 2013). This minority group comprises over 4% of the total UK population (Diabetes UK, 2014). There is evidence to suggest that T2D occurs in the SA population up to a decade or earlier than the Caucasian population (National Institute for Health and Clinical Excellence (NICE), 2012). Moreover, Tillin, Hughes, Godsland, Whincup, Forouhi, Welsh et al. (2012) report SA (Indian) and African Caribbeans have at least twice the risk of developing T2D compared to the Europeans population who were of the same age. They highlight that T2D is particularly prominent in Male SA's (Indian) who were three times more likely to develop T2D than European Males.

1.5. Self-management behaviours

There is currently no cure for T2D, and managed through lifestyle behaviours, therefore, it is important to explore such behaviour towards diabetes management within the SA population (Diabetes UK, 2014; Khunti, Kumar, & Brodie, 2009; Umeh, 2017). Patient centred care should be offered to people with T2D (NICE, 2009; 2015). 'Treatment and care should take into account individual needs and preferences' (NICE, 2015; 2017, p.8) and individualised care; ‘Adopt an individualised approach to diabetes care that is tailored to the needs and circumstances of adults with type 2 diabetes, taking into account their personal preferences, comorbidities, risks from polypharmacy, and their ability to benefit from long‑term interventions because of reduced life expectancy’ (NICE, 2015; 2017, p.12).

For T2D self-management, the NICE (2017) guidelines recommend essential changes that need to be followed to ensure optimal clinical outcomes; these include: attending structured education and making lifestyle changes such as dietary modifications, taking part in Physical Activity (PA), Self-Monitoring of Blood Glucose (SMBG) and taking medication (*Self-management behaviours are discussed in more detail in section 2.2*).

It is noteworthy that different countries have their specific (and variable) self-management guidelines, for example, in the USA The American Association of Diabetes Educators (AADE), (2014) have suggested 7 self-care behaviours for positive diabetes management: healthy eating, being active, monitoring, taking medication, problem-solving, healthy coping, and reducing risk. In addition to the four lifestyle changes that NICE (2009; 2015; 2017) (UK) recommends, the AADE promotes skill development in problem-solving although broadly these behaviours are assumed to be incorporated into NICE service applications For this PhD, the UK NICE (2015; 2017) guidelines for diabetes self-management have been adopted.

1.6. Theories of behaviour change

There are a number of health psychology models and or theories that have been developed to help understand behaviour change. Health psychology is a branch of psychology that deals with how people cope, manage illness, health behaviour and essentially learn to empower themselves (Ogden, 2007). Many theoretical perspectives exist to help understand health behaviour which include; Biopsychosocial Model (Engel, 1977), Health Belief Model (HBM) (Rosenstock, 1974), Trans-theoretical Model (TTM) (Prochaska & DiClemente, 1986), The Protection Motivation Theory (PMT) (Rogers, 1983) and Theory of Planned Behaviour (TPB) (Fishbein & Ajzen, 1975). It can be argued that these hypo-deductive models are global and generic (Coulson, Ferguson, Henshaw & Heffernan, 2016; Taylor, Bury, Campling, Carter, Garfied, Newbould & Rennie, 2007). Given the diversity of the SA population and the prevalence of diabetes (Hanif & Karamat, 2009), this PhD proposes that these models do not apply particularly well to a problem that is endemic in a minority ethnic group of a highly diverse heterogeneous nature. Previous literature has recognised that the health psychology models used previously have not considered the cultural and religious idiosyncrasies of being SA (e.g. being Hindu or Muslim and living in the SA community and having diabetes) (Dutta & Basu, 2011). There is a need to evolve the current understanding of T2D self-management behaviours and explore aspects of culture and religion within this understanding.

As diabetes self-management focuses on behaviour change adopting a health psychology underpinning has been chosen, as this field of psychology aims to focus on generating, testing and implementing the theory into practice (Ogden, 2012). This PhD used Grounded Theory (GT) methodology (Strauss & Corbin, 1990) to develop a theory, specifically to consider the cultural, ethnic and religious nuances that may exist for the SA population with T2D.

Chapter 2: A Literature review exploring adherence to T2D self-management behaviours within the UK SA population

Literature review – Chapter overview

This literature review discusses the existing research on adherence to self-management in T2D in the SA population, focussing on the lifestyle strategies recommended as outlined in (*Chapter 1, sub-section: 1.5*), i.e. diet, exercise, medication and SMBG. This literature review highlights the evidence around the health disparities that exist in the SA population and factors that influence self-management leading to poor outcomes.

2.1. Prevalence and health disparities of T2D in SA population

Evidence suggests that health disparities with diabetes prevalence exist in SA population compared to European counterparts (Bhopal, 2013; Modesti, Perticone, Parati Rosei, & Prisco, 2016; Sattar, & Gill, 2015; UK Prospective Diabetes Study Group, 2004). Although there is no definitive explanation as to why the SA population are more pre-disposed to T2D, there have been attempts made to explore this further. Earlier evidence has highlighted a number of contributing factors such as higher rates of obesity in the SA population; genetic factors, increased fat distribution (which results in more insulin resistance compared to the Caucasian population); socioeconomic status (SES); lifestyle factors e.g. nutrition dynamics and the fact that the SA population are less likely to engage in PA (Beihl, Liese, & Haffner, 2009; Hayes, White, Unwin, Bhopal, Fischbacher, Harland, & Alberti, 2002; Tillin, Hughes, Mayet, Whincup, Sattar, Forouhi et al., 2013; Zaninotto, Mindell, & Hirani, 2007). This is further explained in sections 2.2, 2.3, 2.4, 2.5, 2.6, 2.7 and 2.8.

A recent meta-analysis (Meeks, Freitas-Da-Silva, Adeyemo, Beune, Modesti, Strons, et al., 2016) systematically quantified the risk differences across various ethnic groups compared to the European population. The results suggested that the SA population had the highest odds (almost four times more likely) of developing T2D compared to the European group (3.7, 95% CI 2.7 -5.1). Moreover, this review suggested that there was significant variation (*see pages 37-38 for sub-group context*) in T2D within the heterogeneous SA sub-groups. Specifically, Bangladeshi participants had the highest odds ratio of 6.2 (95 % CI 3.9–9.8) compared to Pakistani participants (5.4, 95 % CI 3.2–9.3) followed by the Indian participants (4.1, 95 % CI 3.0–5.7). While previous literature has acknowledged variation of T2D within SA sub-groups (Bhopal et al., 1999), there is limited research that has explored and compared T2D behaviour, experiences or care within these SA groups. This is important given the practical context that individuals are categorised as either SA or ethnic minority in healthcare (Bhopal et al., 1999) and not considered as a distinct sub-group such as Pakistani/Bangladeshi/Indian despite these known differences.

2.2. What is self-management?

NICE (2015; 2017) has recommended specific self-management behaviours (*as described in chapter 1, section 1.5*). However, there is no universally recognised definition of the term ‘self-management’ According to NHS England (2017) *‘People have a key role in protecting their own health, choosing appropriate treatments and managing long-term conditions. Self-management is a term used to include all the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the healthcare system’.* McGowen (2005) suggests that self-management is an individual interpretation of behaviours into their daily lifestyle.

Self-management can be complicated due to the nature of the regime involved (e.g. diet, exercise, SMBG and taking oral medication and in some cases insulin). However, often people report varied adherence, which affects their diabetes outcomes (Cramer, 2004; Johnson, 1992). Evidence suggests that self-management is vital to achieve successful outcomes and prevent complications, such as neuropathy, nephropathy and retinopathy (Beverly, Fitzgerald, Sitnikov, Ganda, Caballero, & Weinger, 2013; Gomersall, Madhill, & Summers, 2011; Weaver, Lemonde, Payman, & Goodman, 2014). Depending on the needs of the person with T2D diabetes, NICE (2015) outlines specific treatment and outcome targets.

Glycated haemoglobin (HbA1c) identifies average plasma glucose concentration within the blood. HbA1c develops when haemoglobin has become glycated (by combining glucose within the blood) (Diabetes.co.uk, 2017). A HbA1c test is used to measure individual’s glucose control (Jia, 2016).

Table 2.1**:** Target HbA1c

Treatment	HbA1c	Blood pressure
Lifestyle and diet, and/or with a single drug	48 mmol/mol (6.5%)	Below 140/80 mmHg
Drug-associated with hypoglycaemia	53 mmol/mol (7.0%)	

NICE (2015) recommends that if adults are not adequately controlling their diabetes with their medication and their HbA1c rises to 58 mmol/mol (7.5%) or higher health professionals should reinforce the importance of making appropriate changes to achieve the target HbA1c level (*Table 2.1*). HbA1c testing is carried out every three months (Tahara & Shima, 1995). In 2012-2013 only 37.3% of patients were recorded as achieving all three treatment targets. While this figure has increased slightly over the past four years, in 2016-2017 40.8% of patients achieved all three targets; this figure remains suboptimal despite significant investment in diabetes services (NHS digital, 2017). To meet these targets patients are encouraged to modify various aspects of their lifestyle, incorporating dietary advice, increasing physical activity, taking medications, monitoring blood glucose and managing appointments with health professionals (Federation of European Nurses in Diabetes, 2014; Frei, Chmiel, Schlöpfer, Birnbaum, Held, & Steurer, et al., 2010; Wilson, 2015).

The SA population have been found to typically have poor diabetes control (Mukhopadhyay, Forouhi, Fisher, Kesson, & Sattar, 2006; Negandhi, Ghouri, Colhoun, Fischbacher, Lindsay, & McKnight et al., 2013; Soljak, Majeed, Eliahoo, & Dornhorst, 2007). NICE (2015; 2017) recommends people with T2D should be aiming to achieve three treatment targets: relating to glucose control, blood pressure, and serum cholesterol. When these goals are met, they reduce the risk of people developing complications. Previous literature has highlighted a range of factors, which may influence diabetes self-management in the SA population (Basu & Garg, 2017; Bellary, O'Hare, Raymond, Gumber, Mughal, Szczepura, et al., 2008; Majeed-Ariss, Jackson, Knapp, & Cheater, 2013; Osman & Curzio, 2012). There are growing concerns that some SA patients with T2D fail to manage their condition in accordance with clinical guidelines (Pardhan & Mahomed, 2004), thereby increasing the risk of diabetes-related complications, and/or premature mortality (Bajaj, Jawad, Islam, Mahtab, Bhattarai, & Shrestha, et al., 2013; Barnett, Dixon, Bellary, Hanif, O’Hare, Raymond, et al., 2006; Gholap, Davies, Patel, Sattar, & Khunti, 2011). For example, SA patients had poor blood glucose control with higher HbA1c compared to Caucasians (Bhurji, Javer, Gasevic, & Khan, 2016; Singh, Cinnirella, & Bradley, 2012), were less likely to comply to prescription medications (Kumar, Greenfield, Raza, Gill, & Stack, 2016), did not engage with regular physical activity (Ranasinghe, Ranasinghe, Jayawardena, & Misra, 2013), and ate foods with high glycaemic index values (Merchant, Anand, Kelemen, Vuksan, Jacobs, Davis, et al., 2007). A review by Hill (2007), highlighted challenges SA patients face with regards to diabetes management, which suggested health professionals should be able to acknowledge SA language requirements and have some understanding of cultural needs specifically towards elements of self-management such as diet, exercise, SMBG and adherence to medication. Bromley Healthcare CIC (Wright & Buchczyk, 2015) commissioned a report that explored attitudes towards diabetes in SA communities. The project consisted of interviewing experts, carrying out ethnographic fieldwork and in-depth interviews. The report highlighted three relevant themes to help aid understanding of diabetes self-management. The first theme explored how diabetes was seen as unavoidable and ‘normal’, and there was a sense of denial within the community as it was perceived diabetes was temporary, and this influenced their attitudes toward accepting the behavioural changes that are needed to manage diabetes. Cultural and religious influence towards diet and PA were identified as the second theme; emphasis was made that food was an important aspect in the community, making changes and adhering to advice was difficult. Amongst the SA participants, exercise was not perceived to be part of their ‘SA’ identity and that women should exercise at home as part of their routine. The final theme was around confusion and distrust toward the health system, in particular, understanding of medication and insulin, a preference towards natural remedies was widely accepted in the community. This report indicates that SA populations face some barriers that need to be explored further (Holt, 2012).

2.3. Diet

A healthy diet plays a significant part in living with T2D (Knutsen, Foss, Todorova, Roukova, Kennedy, Portillo, et al., 2017; Vanstone, Rewegan, Brundisini, Giacomini, Kandasamy, & DeJean, 2017). According to NICE (2015), a dietitian should tailor advice to individual needs taking into account culture and beliefs. It is recommended that the guidance should include information around timings to eat, information on healthy eating; consumption of carbohydrate (including fruit and vegetables, whole grains and pulses), low-fat dairy products, oily fish and limited saturated fats, trans fatty acids and alcohol intake. Diabetes UK (2018) have updated their dietary recommendations for health professionals and have now included the statement ‘adopt a person-centered approach and a variety of learning styles during education’. This recent addition of the words person-centered recognises the need to tailor dietary advice to individual needs rather than offering blanket dietary advice for those with diabetes.

Taking on dietary modifications can be difficult regardless of ethnicity (Gray, Millett, Saxena, Netuveli, Khunti, & Majeed, 2007; Lerman, 2005; Ley, Hamdy, Mohan, & Hu, 2014; Mohan, Radhika, Sathya, Tamil, Ganesan, & Sudha, 2009). Diet has been suggested to be the leading cause of poor diabetes control (Sundaram, Kavookjian, Patrick, Miller, Madhavan, & Scott, 2007), especially within the UK SA community (Singh & Bradley, 2006). Previous studies have reported dietary disparities between the SA population and the European population (Donin, 2010; Garduno-Diaz, & Khokhar, 2012; Holmboe-Ottesen & Wandel, 2012; McKeigue, Shah, & Marmot, 1991; Wandel, Råberg, Kumar, & Holmboe-Ottesen, 2008; Wyke & Landman, 1997). It is important to note, that although dietary disparities exist between SA population and the European population, there is also evidence to suggest that it exists and varies within the different sub-groups of SA population (Smith, Knight, Sahota, Kernohan, & Baker, 1995; Williams, Bhopal, & Hunt, 1994). For example, a study carried out in Coventry, UK (Simmons & Williams, 1997) explored the dietary practices of Europeans and SA living with diabetes. The study recruited five SA sub-groups (Punjabi Sikhs, Pakistani/Punjabi Moslems (Muslims), Gujarati Moslems (Muslims), Punjabi Hindus and Gujarati Hindus). The study showed that the Gujarati group consumed higher amounts of fried snacks, white flour and rice. The Muslim cohort were least likely to be vegetarians and prepared food with homemade ghee and yoghurt. The Punjabi Sikhs and Hindus reported eating dhal more often than the other sub-groups. This important variation and diversity in food consumption warrant further exploration. The documented evidence to date highlights that the SA diet has been a contributing factor in increased blood glucose levels, although such evidence does not investigate these variations in the diversity of SA diet.

Carr (2012) conducted a literature review exploring dietary advice to people with T2D. This review focussed on participants from ethnic minorities (not just SA participants), a sample of studies within the review included SA participants. The review emphasised the need for dietary advice to be tailored towards individual needs and to consider cultural and religious influences on eating habits (Ikeda, 2004).

A recent mixed methods study (Emadian, England & Thompson, 2017) explored dietary intake among overweight and obese SA men living in the UK. The quantitative component of the study employed the UK Diet and Diabetes Questionnaire (England, Thompson, Jago, Cooper & Andrews, 2017) which revealed that overall 54% of SA men had a ‘healthy’ diet. However, participants did have specific areas for dietary improvement. For example, the majority (69%) of participants reported excessive intakes of sugar-sweetened liquid drinks. The qualitative element to the study explored attitudes to improve diet. However, it is noteworthy that the investigation of specific cultural foods (such as ghee/ Indian sweets) was not explicitly investigated. These findings highlight that while there has been some attempt to explore dietary practices in SA individuals, such studies have not necessarily considered cultural, ethnic or religious influences in dietary consumption and behaviour. This study highlighted that a significant proportion of SA men reported high intake of sugar-sweetened liquid drinks. It is not clear what this means exactly, but it is possible that it could be an important factor that needs to be given attention and further exploration. Although there is evidence to suggest that diet plays a role in ensuring effective management of T2D, the research specifically in the SA population and the effects food has on T2D is still variable under-investigated and appears to remain highly variable (Hempler, Nicic, Ewers, & Willaing, 2015).

2.4. Physical Activity (PA)

PA is a core aspect of T2D self-management and a healthy lifestyle (Colberg, Sigal, Fernhall, Regensteiner, Blissmer, Rubin, et al., 2010; Thomas, Elliott, & Naughton, 2006; Umpierre, Ribeiro, Kramer, Leitão, Zucatti, Azevedo, et al., 2011). NICE guidelines (2018) state that physical activity can reduce the risk over 20 health conditions including diabetes prevention, as well as reduce the risk of cardiovascular disease, cancer, joint and back pain, depression and dementia.

The UK Chief Medical Officers' (Public Health England, 2016) recommend adults engage in at least 150 minutes of moderate intensity PA (e.g. brisk walking) or vigorous activity (e.g. running) per week; plus, strength activities (muscle training) on two or more days per week (or engage in a mixture of moderate and vigorous PA and strength activities). Despite these recommendations, statistics show there are still large numbers of people across the UK who are failing to engage in PA at this level, which is likely to have a negative impact on their health. Specifically, around 39% of UK adults are not meeting government recommendations for PA. The North West of England has the highest proportion of people who are not meeting the PA recommendations (British Heart Foundation, 2017; Care Quality Commissioner (CQC), 2016).

The SA group within the North-west is diverse, as previously highlighted (*Chapter 1, page 39 – sub section 1.3)* evidence reports that individuals from SA descent engage in low levels of PA (Hayes et al., 2002; Lean, Han, Bush, Anderson, Bradby, & Williams, 2001; Waidyatilaka, Lanerolle, Wickremasinghe, Atukorala, Somasundaram, & de Silva, 2013; Williams, Stamatakis, Chandola & Hamer, 2011). It has been identified that the UK SA population have shown not to partake in as much physical activity as the general population (Bhatnagar, Townsend, Shaw, & Foster, 2015; Hayes et al., 2002; Cross-Bardell, George, Bhoday, Tuomainen, Qureshi, and Kai, 2015).

There is some evidence to suggest that there are additional disparities of engaging in PA within SA population sub-groups (Fischbacher, Hunt, & Alexander, 2004). For example, the Bangladeshi population have been found to report lower levels of PA compared to the Indian community (Rudat, 1994; Hayes et al., 2002).

For those with a diagnosis of T2D, PA is an essential component of self-management. NICE (2009) recommends that as part of a personalised diabetes management plan, patients should be encouraged to increase physical activity and lose weight. Regular moderate intensity PA improves short- and long-term glycemic control for those with T2D (NICE, 2018). Regular PA for those with T2D may reduce the amount of T2D medications required (Asif, 2014; Wing, Epstein, Paternostro-Bayles, Kriska, Nowalk, & Gooding, 1988). PA has been shown to support weight loss and weight maintenance (weight loss identified as a beneficial aspect to diabetes self-management (Colberg et al., 2010; Swift, Johannsen, Lavie, Earnest, & Church, 2014) when used in conjunction with diet. A research study found that low-intensity exercise was equally useful as a high-intensity exercise for improving glucose control in individuals with diabetes (Hansen, Dendale, Jonkers, Beelen, Manders, & Corluy, 2009).

For patients who are SA and living with T2D, it is important to explore the motivations, barriers and experiences of engaging in PA. Carroll, Ali, and Azam (2002) reported tailored exercise on prescription schemes could be successful. Cost, cultural and language barriers were identified as reasons for low-level PA engagement, influenced by religious restrictions and limited facilities, (e.g. lack of appropriate female-only facilities) (Farooqi, Nagra, Edgar & Khunti, 2000; Sriskanthatrajah & Kai, 2006; Khatoon, 2006). Moreover, when services were available, some Muslim women had a lack of confidence to attend exercise classes (Grace, Begum, Subhani, Kopelman, and Greenhalgh, 2008). Barriers such as time and motivation have also been highlighted in the literature for this population, especially for women. A recent mixed methods study conducted by Emadian and Thompson (2017), measured PA, sedentary time and explored factors influencing these behaviours in SA people with T2D. In line with previous research, this study concluded that lack of time and family commitments (e.g. childcare) were found act as barriers (Farooqi, Nagra, Edgar & Khunti, 2000; Sriskantharajah & Jai, 2006). Although many barriers and factors influence PA, there is still a need to develop successful interventions amongst the UK SA population especially understanding the needs of SA women (Babskus & Thompson, 2012).

Chapman, Qureshi and Kai (2013) systematically reviewed the effectiveness of PA and dietary interventions in the SA population. A total of

119 articles were considered. However, only four studies met the specified inclusion criteria. While a small-scale review it concluded there was potential for interventions to improve diet and PA, although, the findings did not reach to any concrete conclusions to suggest which interventions were most successful. The review did highlight the need for future research that could help investigate successful interventions aimed at SA population. Specifically, it recommended qualitative work aimed at the SA population, targeting educational, behavioural and motivation components for individuals to engage with PA interventions.

More recently, Albalawi, Coulter, Ghourid and Paul (2017) carried out a review looking at the effect of exercise interventions (aerobic, resistance, balance or combined exercise programmes) in SA's with T2D. The findings suggested that exercise interventions improved glycaemic control, waist circumference and quality of life. However, the type of exercises which promoted these positive outcomes (aerobic, resistance, balance or combined exercise programmes) was not specifically reported. The findings of this review concluded that methodological limitations were apparent in the studies. The review suggested tailored PA interventions for SA with T2D may be useful although highlighted a clear need for further quantitative and qualitative research on this topic.

The DiRECT trial is a recently published study which aimed to assess if intensive weight management would achieve remission of T2D. The clustered-randomised trial was carried in 49 practices with 306 participants who had been diagnosed with T2D within the past six years. The participants in the intervention group followed the Counterweight-Plus programme delivered by trained nurse or dietitian. By following a low energy formula diet participants aimed to loose at least 15kg weight and monthly visits were carried to maintain their long-term weight loss goal. Diabetes remission was achieved in 68% if the intervention group and 4% in the control group. The findings suggest that remission of T2D can be achieved and it is not a lifelong or permanent condition (Lean, Leslie, Barnes, Brosnahan, Thorn, McCombie et al, 2018).

2.5. Medication

Patients should receive healthcare advice and interventions to manage both blood pressure and blood-glucose (NICE, 2015). Patients are prescribed medication if lifestyle management (diet and PA) do not reduce blood pressure to below clinical target (140/80 mmHg, NICE, 2015) or if blood glucose targets (Hba1c) are not met. Patients will be prescribed metformin as the initial drug treatment. Although additional medications (e.g. dipeptidyl peptidase‑4 (DPP‑4) inhibitor or pioglitazone or a sulfonylurea (Pathak & Bridgeman, 2010) or insulin may also be prescribed if required.

Medication adherence in T2D is recognised as an ongoing difficulty (Krass, Schieback, & Dhippayom, 2014). Medication management has not been a specific topic of research for the SA population as there is limited research on this particular aspect of self-management behaviour. However, of the available research, it is suggested that the SA population have poorer medication adherence compared to other ethnic groups (Chong, Wang, King-Shier, Quan, Rabi, & Khan, 2014). A recent qualitative synthesis conducted by Kumar, Greenfield, Raza, Gill and Stack (2016) concluded that confounding cultural beliefs shape individuals' decisions in taking medication as prescribed. Specifically, Kumar and colleagues highlighted the existence of cultural and social stigmas associated with adhering to medication.

Another review has evaluated the 'barriers' to medication adherence in SA's (Sohal, Sohal, King-Shier, & Khan, 2015), and suggest that patients present a lack of understanding about their medication, which encourages them to change their dosage/adherence independently. In the SA population, medication is perceived to aid the 'sick' role and is considered harmful. Both Kumar et al., 2016 and Sohal et al., 2015 refer to the SA preferences towards herbal supplements to control and prevent disease, rather than adhering to traditional medication advice and prescription.

A qualitative study conducted by Patel and colleagues (2014) explored the beliefs and experiences of 23 Muslim patients fasting during Ramadan. The results from this study found that patients were altering their medication and diet during this period. It was reported that these decisions to change their medications stemmed from family and social pressures, who placed priority on religious (fasting) behaviours rather than healthcare behaviours.

Interestingly, Patel, Kennedy, Blickem, Reeves, and Chew-Graham (2016) studied how social networks and beliefs played a role for SA patients while on holiday visiting the Eastern countries. This research suggested there was a lack of understanding and importance place on medication alterations while on holiday. The participants were influenced heavily by friends and family who interfered with their behavioural lifestyle choices. These social networks changed the individual's perception of and importance placed on T2D management, especially during the holiday periods.

As the findings above suggest, behaviours carried out towards medication adherence are primarily influenced by beliefs. However, there is a need to explore adherence to medication in the SA population further and investigate how SA patients may be facilitated to better adhere to advice and medication prescribed (Alhomoud, Dhillon, Aslanpour, & Smith, 2015).

2.6. Self-monitoring of blood glucose (SMBG)

NICE states that SMBG is not routinely recommended as a self-management behaviour, unless the individual is on insulin, or has consistent hypoglycemic incidents, or on additional medications or pregnant (NICE, 2015). There is no consistency in the evidence to suggest SMBG improves diabetes self-management (Clar, Barnard, Cummins, Royle & Waugh, 2010; Parsons, Luzio, Bain, Harvey, McKenna, Khan, et al., 2017). There is some evidence to suggest that SMBG empowers people with T2D and help them to feel more in control (Barnard, Loveman, 2008; Speight, Browne & Furler, 2015). Although some evidence suggests that SMBG may not encourage patients to act and make adjustable changes, thus SMBG may not be an effective self-management strategy (Franciosi, Pellegrini, De Berardis, Belfiglio, Cavaliere, Di Nardo, et al., 2001). Of the literature which does consider SMBG in T2D, most have focussed on Caucasian populations and concluded that SMBG was found to increase awareness of blood glucose levels but may also prompt psychological factors such as increased anxiety and guilt (Barnard, Young & Waugh, 2010). A qualitative meta-synthesis of patient experiences of SMBG Chen, & Chang Yeh (2015), revealed that individuals might experience various psychological issues associated with SMBG. Specifically, patients may experience cognitive misconceptions which may induce negative emotions. However, the review highlights the need for further research on the influence of SMBG on patient's mental health and quality of life. One study included in this meta-synthesis specifically explored the view Black Caribbean and SA. While it was noted SMBG may trigger negative emotions (e.g. disappointment), this research also highlighted that SMBG also triggered positive emotions (reinforcement, happiness, prompted compliance).

2.7. Factors influencing adherence to self-management

NICE (2015, p.12) recommends patients are offered 'individualised care', this is an approach that is "tailored to the needs and circumstances of adults withT2D, taking into account their personal preferences, comorbidities, risks from polypharmacy, and their ability to benefit from long-term interventions" p.12. In addition, services should "meet the cultural, linguistic, cognitive and literacy needs within the local area."

A recent health care report (CQC, 2016) explored people's experiences of community diabetes care and suggested that most people reported improvement overall as attending structured education improved their knowledge, but care and support were not always flexible and responsive enough to meet everyone's individual needs. In addition, the report highlighted the limited extent to which services were successfully supporting people to self-manage (p.15).

Previous literature has highlighted a significant link between social/cultural/religious factors contributing towards self-management for the SA population (Alhomoud, Dhillon, Aslanpour, & Smith, 2013; Cappuccio, Cook, Atkinson, & Strazzullo, 1997; Keval, 2009; Patel, Kennedy, Blickem, Reeves, & Chew-Graham, 2015). In relation to the cultural context, Patel and colleagues (2015) explored the influence of sociocultural contexts on illness beliefs and diabetes self-management. The mixed method study found that social networks (i.e. family members) were related to perceived concern, and the qualitative data suggested that fatalistic attitudes (e.g. chance or bad luck) and causal beliefs (genetics, diet) suggested by social networks shaped patient's beliefs towards T2D self-management. Another research study, the Diabetes and Me project was delivered in Scotland; the aim was to engage SA communities by utilising three different models to raise public awareness, provide focussed and tailored support sessions led by trained volunteers, and work collaboratively with local service providers. This project reached a wide group and concluded that the models were successful in changing beliefs, perceptions and attitudes of the general population, which in turn may be helpful for patients with T2D. Such public awareness approaches tailored towards a specific population may be useful when designing interventions (Bailey, Sattar, & Akhtar, 2018; Seneviratne, Macaden, & McGlynn, 2016).

Religious beliefs have also been found to influence diabetes self-management, especially prominent in SA patients who are Muslim (religious obligation relates directly to dietary and lifestyle habits, e.g. Ramadan) (Hassanein, Abdallah, & Schweizer, 2014; Patel et al., 2014). A study conducted by Naeem (2003), explored the role of culture and religion in the management of diabetes among Pakistani (Kashmiri) men. The findings reported 32% of the participants believed that diabetes was “Allah’s will”, a high proportion of this sample had also been advised that they were overweight, but only 42% recognised this definition (cultural, social norms considered them to be a ‘healthy size’).

2.8. Education

Diabetes education can be a successful tool in enhancing self-management resulting in positive clinical outcomes (Jarvis, Skinner, Carey & Davies, 2010; Khunti, Gray, Skinner, Carey, Realf, Dallosso, & Davies, 2012). There are two established structured education programmes in the UK, which have been rolled out nationwide. The X-PERT programme (Deakin, Cade, Williams, & Greenwood, 2006) and the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) (Department of Health and Diabetes UK, 2005). These have been evaluated for both European and SA groups, and results suggest that those programmes significantly improve clinical outcomes such as improved Hba1c levels and blood pressure (Bourke, Heverin, Dinneen & O'Donnell, 2017; Chatterjee, Davies, Stribling, Farooqi, & Khunti, 2018; Davies, Heller, Skinner, Campbell, Carey, Cradock, et al., 2008; Deakin, Cade, Williams & Greenwood, 2006).

To support patients in T2D self-management NICE (2015; 2017) recommends patients are offered structured education programmes around the time of diagnosis. This education should be evidence-based, offer support to family members; be delivered by trained and competent individuals, and able to meet individual needs, e.g. culture, literacy and language requirements. According to the NICE, (2009), “diabetes structured education is quality assured training that provides people with diabetes, their family and their carers with the knowledge and confidence to self-manage a long-term condition. Diabetes Structured Education courses deliver information, training and support on how to manage diabetes through diet, PA and medication. Essentially they are providing the foundation support for diabetes self-management.”

NHS Digital (2017) reported that in 2013, 54% of patients with T2D were offered structured education within 12 months of diagnosis, and this figure has increased to 77% by 2015. However, it is noteworthy that despite being ‘offered’ education, attendance at such education remains very low (only 6.4% of patients attended structured education, in 2013 increasing to 7.1% by 2015) (NHS digital, 2017). It is noteworthy that of those 7.1% of patients who did attend it is not known how many of those were from ethnic minorities. Although evidence suggests that SA patients have difficulties with diabetes self-management, specifically, poor glycaemic control, non-adherence to dietary/PA guidelines, or medication usage, less contact with doctors/nurses, compared to Caucasians (Bhurji, et al., 2016; Gray et al., 2007) suggesting poor uptake of education programmes in ethnic minority groups

There has been some development and adaptation to T2D education programmes claiming to adapt content and delivery for specific patient cohorts, e.g. minority groups (Marwa, Mughal, Sunsoa, & Bibi, 2004). As NICE guidelines state, structured education needs to be adapted to individuals' culture and or religion, however, while this comment is in NICE guidelines, it is not clear how healthcare professionals or services should do this. Attempts have been made to develop education programmes specific to the Muslim population (specific religious influences, e.g. for the month of Ramadan (Almalki, Hussen, Khan, Almaghamsi, & Alshahrani, 2018).

Bravis, Hui, Salih, Mehar, Hassanein, and Devendra (2010) compared two groups of patients. One group (A) attended a structured education, and the other group (B) did not. The results demonstrated significant improvements in clinical and medical outcomes, for example, group A reported a decrease in hypoglycemic events from nine to five, where group B reported an increase from nine to 36. This indicates when services personalise education towards cultural needs (rather than simply interpreting programmes into another language) can lead to positive outcomes.

The aim of the education is to improve people's knowledge and skills and promote self-responsibility (Bagnasco, Di Giacomo, Da Rin Della Mora, Catania, Turci, Rocco, et al., 2014; Chrvala, Sherr, & Lipman, 2016; Haas, Maryniuk, Beck, Cox, Duker, Edwards, et al., 2012; Hoving, Visser, Mullen, &

van den Borne, 2010; McDowell & Grant, 2016; Mutuota, Hill, & Claydon, 2017). Hawthorne and Tomlinson, (1997) designed and evaluated a structured pictorial flashcard programme aimed at for Pakistani patients in Manchester. Attitudes, knowledge and self-caring skills were measured and compared six months later. The results found that knowledge increased, and self-caring behaviour improved, concluding that a health education programme can empower patients to take control of their diabetes. Hawthorne (2001), further tested the pictorial flash card in a sample of 105 British Pakistani women, the findings from this study were similar to the previous study. However, this study highlighted the need to target the deprived populations they showed low improvements.

Stone, Pound, Pancholi, Farooqi, and Khunti (2005) explored experiences and attitudes of diabetes, with a mixed population of SA and Caucasian. The findings highlighted that for the SA population, knowledge of diabetes was lower, and education would help with understanding disease management. The recent CQC (2016) report acknowledged that very few of the people from BME groups had attended a structured education programme, “Most were unaware of these programmes and had not spoken with a health professional about them” (p.17). Some service providers/commissioners reported they had offered education in languages other than English. Despite services suggesting that they had tailored education through foreign language adaptation. The CQC recognised that often services were not appropriate to local communities, a view echoed by local people (CQC, 2016, p.17).

A recent report by Ali, Gilani, and Patel (2017) highlighted that health professionals could tackle health inequalities by delivering basic cultural tailored education. This has been supported in a project: South Asian Community Health Education and Empowerment, this project delivered 11 SA tailored education events to increase knowledge and understanding of diabetes self-management. Although no scientific claims could be carried out due to the participation numbers, an attempt was made to evaluate the programme by distributing a questionnaire. The analysis suggested that the education sessions increased knowledge by 10-15%, e.g. awareness of the link between diabetes and obesity. This project implied that simple tailored educational sessions could lead to increased knowledge and understanding, therefore could lead to positive self-management and behaviour change.

Indeed, while services have been criticised above for not adapting education to cultural needs. There is also a need to provide services in appropriate languages for all patients. Language has been identified as in issue for the SA population specifically in access to services and quality of care (Alam, Speed, & Beaver, 2012; Rhodes & Wright, 2003). The ONS reported 726,000 people could not speak English well and 138,000 people could not speak English at all (ONS, 2011 p.2). According to the ONS, the majority of the SA population spoke Panjabi (273,000 people) or Urdu (269,000) followed by Bengali (Sylheti and Chatgaya, 221,000) and Gujarati (213,000) (ONS, 2011, p.3). Ahmed, Abel, Lloyd, Burt and Roland, (2015) analysed data from the 2010/2011 English General Practice Patient Survey, to explore doctor-patient communication. The study included SA and White British patients and concluded that SA people preferred to be seen by a doctor of the same ethnicity as this made communication easier. Overall, SA patients reported poorer experiences of doctor-patient communication than the White British patients.

There has been an attempt to overcome language difficulties by integrating bi-lingual health workers into healthcare. A consultation in Tameside, Greater Manchester was carried out in 1990, where issues and barriers towards self-care in diabetes were discussed. As a result, diabetes support workers were trained to provide a language-specific service, which was deemed helpful to the SA community (Curtis, Beirne, & Jude, 2003). Although considered a successful project, systematic role out of such an approach was not adopted. It is, however, noteworthy that language translation can be limited and may cause additional issues if not implemented correctly. For example, interpreters may change the meaning of healthcare interactions and understandings. Healthcare consultations are time-limited, and services have limited resources available to ensure effective and accessible translation services (Hadziabdic, Heikkilä, Albin, & Hjelm, 2011; Li, Pearson & Escott, 2010).

Some studies have attempted to gain an understanding of factors contributing to service use in SA groups. Alam, Singleton, and Strut (2008) carried out a review of evidence regarding the effectiveness of diabetes health education, for Bangladeshi patients. The report concluded that community-led interventions were successful but lacked uptake and attendance. Suggesting a need to understand how to communicate, motivate and appeal to such specific population groups. Low literacy has been found to influence diabetes knowledge (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013; Bailey, Brega, Crutchfield, Elasy, Herr, Kaphingst, et al., 2014). Health literacy skills had been identified as an important element in diabetes management (McDowell & Grant, 2016). Estacio, McKinley, Saidy-Khan, Karic, Clark, and Kurth (2015) explored health literacy needs of SA men and concluded that language was a specific barrier contributing to poor health literacy. These two issues are separate but very important as simple interventions such as simply translating leaflets, to provide healthcare information may not be sufficient. There is evidence to suggest that some people may not be able to read their own language (Khunti, Kumar, & Brodie, 2009; Marwa, Mughal, Sunsoa, & Bibi, 2004).

There is a wealth of evidence to suggest that social support and healthcare support are beneficial in helping a patient engage with T2D self-management. In a recent article Leong, Sanghera, Jhajj, Desai, Jammu, and Makowsky (2017) reviewed YouTube information about T2D tailored towards the SA population. The search revealed that some content was misleading and there was a lack of good-quality videos specifically for the SA community. This review concluded that using the internet as a platform to provide knowledge can be useful. However, there is a need to develop an evidence-based practice where it is tailored towards SA needs.

Cross-Bardell et al. (2015) explored health promotion to enhance PA and exercise within the SA population living in the East Midlands. The study concluded that integrating walking as a method of PA can improve uptake. Challenges faced with SA diet identified that the advice received was not culturally adaptable. The findings suggest that the SA population face complex health issues and require further support, e.g. peer support, bilingual community leaders, and the delivery of any health-related session should be in an informal setting and within the community, for example, a patients home.

A recent systematic review carried out by Bhurji et al. (2016) evaluated studies on the effect of interventions targeted at SA patients T2D glycaemic control. This review combined interventions between India and Western countries. India favoured practical interventions, e.g. Yoga, community peers and cooking classes, whereas in the Western interventions focussed more towards education and information, e.g. written, visual aids, diabetes education. The review concluded that interventions targeted at SA populations led to little improvement in the Western countries compared to India, indicating that interventions which implemented practical advice were considered more personal to the target population, thus more likely to demonstrate improvement.

Baradaran, Knill-Jones, Wallia, and Rodgers (2006) investigated the effectiveness of a diabetes education program for SAs. The intervention group had a 12.5% increase in knowledge scores and a 13.5% increase in deeper understanding of the seriousness of their disease, whereas the control group had no significant improvements (except for a deeper understanding of the severity of their disease), indicating that tailored education is more effective. There is evidence to suggest that culturally tailored interventions can lead to positive outcomes. (Bellary et al., 2008;

Creamer, Attridge, Ramsden, Cannings-John, & Hawthorne, 2015; Hawthorne, Robles, Cannings-John, & Edwards, 2010; O'Hare, Raymond, Mughal, Dodd, Hanif, Ahmad, et al., 2004; Srimanunthipol, Beddow, & Arakaki, 2000). However, there is some contradictory evidence to suggest that cultural education may not have long-term effects as clinical outcomes have been difficult to measure (Hawthorne, Robles, Cannings-John, & Edwards, 2008). There is paucity in the literature to identify which key features are most adaptable and which to roll out in the NHS. Contributing factors identified are poor participation and low up-take which have made evaluations difficult (Hussain-Gambles, Atkin & Leese, 2004; Quay, Frimer, Janssen, & Lamers, 2017).

2.9. Summary

Together the studies reviewed thus far provide important insights into factors that influence diabetes self-management. The current literature helps to understand the factors that are relevant to the SA population who have a diagnosis of T2D. However, simply identifying the factors is not enough, to implement behaviour change it is important to look at the psychological aspects that explain the behaviour and then implement strategies for successful behaviour change.

Many educational interventions are focussed on understanding diabetes as a condition. To develop effective behaviour change interventions, it is important to look at how to encourage people to respond to health information. The literature review provides an insight into contributing factors. However, the evidence base is inconclusive with regards to making fixed recommendations when it comes to health promotion in the UK SA population. Recent concerns about the high prevalence of T2D, more specifically in the SA population has led to concerns which require further exploration. This thesis provides an opportunity to explore the psychological underpinnings linked to improving adherence to T2D self-management in the SA population.

Chapter 3: A systematic review and meta-synthesis relating to T2D self-management behaviours within the UK SA population.

Meta-synthesis - Chapter overview

A Critical Interpretive Synthesis (CIS) (Dixon-Woods, Cavers, Agarwal, Annandale, Arthur, Harvey, et al., 2006) was conducted on published qualitative literature with the aim of presenting a new integrated, descriptive, and explanatory interpretation of SA patients' experiences of adhering to T2D self-management behaviours. The searching of EBSCOhost and grey literature occurred between April 2014 and July 2016 and in total 17 articles were subject to appraisal and review.

The synthesising argument revealed two core synthetic constructs cultural identity; and decisional conflict, these characterised by three second-order constructs; daily lifestyle/ roles influence behaviour; doctor-patient relationship and; beliefs and implementation; leading to the defensive avoidance as an outcome in self-management behaviours. The findings highlighted that cultural identity played a key role in influencing patient's management of diabetes. In particular, tensions between cultural pressures (e.g. religious obligations, personal beliefs, and lifestyle) and medical demands (e.g. doctors' advice, medication adherence) created decision-making dilemmas that hampered self-management.

Overall, SA patients reported a deeply embedded cultural identity, which was prioritised above diabetes medical demands (described as cultural-versus-diabetes conflicts). These conflicts influenced behavioural decisions, which negatively interfered with diabetes self-management.

3.1. Introduction

The previous chapter (2) highlighted diabetes self-management literature exploring UK SA patients. The evidence suggests several cultural barriers that interfere with diabetes self-management were identified, suggesting further exploration of self-management behaviours is warranted.

To date, two reviews of qualitative studies have been published on diabetes self-management in the SA population (Sohal et al., 2015; Fleming & Gillibrand, 2009). These reviews were based on SA patient’s views, beliefs and experiences of diabetes management. Fleming & Gillibrand’s (2009) review utilised theory explication (deconstruct, reconstruct and reconceptualise) to generate new knowledge. Sohal et al., (2015) review analysed their findings using meta-ethnography. The articles included participants from diverse SA ethnic backgrounds such as Indian Malaysian, Bangladeshi, Pakistani, White Kashmiri, Afro-Caribbean, and Indian. The reviews included studies conducted across the world, although did not focus specifically on UK SA population. The NHS is unique to the UK, diabetes care and our comprehensive healthcare service and delivery influence self-management practices. It is essential to take into account the growing diversity of the UK SA population (Darlington et al., 2015; Owen, 2013) and as such further research needs to investigate self-management behaviours.

Fleming & Gillibrand's (2009) review referred to 11 articles, published between 1992-2005. However, one publication (Kelleher & Islam, 1994) appeared to be a preliminary analysis of a large data set, (as also presented in a second study but included within the 11 articles) (Kelleher & Islam, 1996). In addition, one qualitative study appeared to be a 'salami publication' (Šupak Smolčić, 2013), one study published across two publications (Chowdhury, Helman & Greenhalgh, 2000; Greenhalgh, Helman & Chowdhury, 1998), therefore, the review referred to 11 articles, but this referred to nine empirical studies.

Sohal et al., (2015) included 20 articles, published between 1999-2013, of which 13 of these were published prior to 2010. It is noteworthy that the evidence presented across the two reviews is dated somewhat, given 1) the significant increases in T2D prevalence in SA UK population since 2010 (Bhopal, 2013; Meeks et al., 2016; Sattar, & Gill, 2015; Modesti et al., 2016; Tillin et al., 2013) and 2) significant changes to healthcare diabetes services within the last 10 years (*Chapter 1*).

These previous reviews provide a foundation to help understand diabetes self-management. Moreover, given the issues of T2D remaining in the SA population; the growth in SA diversity across the UK; and the publication of new research (*Chapter 2),* there is a need to update the evidence-base and conduct a new comprehensive review to understand self-management behaviours. This CIS, (Dixon-Woods et al., 2006) reports a reanalysis and reconstruction of individual qualitative studies to develop a comprehensive insight into the underpinning psychology, which exists behind patient's self-management behaviours.

3.1.1. Aim and Objectives

This review aimed to derive a new conceptual understanding by interrogating existing qualitative studies reporting how SA patients adhere to diabetes care. The objective of this CIS was to provide a context in which to understand the SA patients' health behaviour towards self-management. In addition to providing new insights, the findings of this meta-synthesis informed the subsequent direction of this PhD.

3.2. Methods

3.2.1. Study design

We (research team) adopted a CIS (Dixon-Woods et al., 2006) approach because this is oriented to the conceptual or theoretical development and allows for critical consideration of diverse studies (Dixon-Woods et al., 2006). CIS is an adaptation of meta-ethnography, as well as borrowing techniques from grounded theory. The epistemological position of CIS articulates that of an interpretative stance. The process promotes the development of a new theoretical model of a phenomenon. Hence the CIS is not just a renew but also creating new knowledge on the topic.

A CIS (Dixon-Woods et al., 2006) was conducted on published qualitative literature with the aim to present a new integrated, descriptive, and explanatory interpretation of SA patients' experiences of adhering to T2D self-management behaviours. The CIS process aimed to be critical by rejecting a 'stage' approach and taking an 'explicit orientation towards theory generation' (Dixon-woods et al., 2006, p. 9). This review sought to explore a deeper insight into the experiences on adherence to T2D treatment regimens with SA patients. The specific question remained open to modification in accordance with the CIS process.

3.2.2. Procedure

The search strategy was adaptive. The included databases listed in Appendix 3.1 were thoroughly searched, and articles published up to July 2016 were obtained. To ensure a comprehensive search (in accordance with CIS methodology), a number of additional search strategies were completed, this included hand searching of journals, searching reference lists of identified articles and in addition searching for grey literature.

The search focused on articles relating to identified topics and associated keywords. The topics were Type 2 Diabetes; Adherence; South Asian; Lifestyle; and Qualitative. An example topic, ‘Type 2 Diabetes’ was defined by the keywords: glucose, blood glucose, non-insulin dependent, non-insulin dependent diabetes mellitus (*Appendix 3.2 for a full breakdown of all topics and keyword information*). A decision was made by the team that as a quantitative literature review had already been conducted (*Chapter 2*), the term qualitative ‘AND’ was attached to all the search terms. Inclusion and exclusion criteria (*Table 3.1*) were agreed between authors.

The search was conducted by the lead researcher who followed a screening process (as informed by Saini & Shlonsky, 2012, p. 102-108). This search and data extraction was an iterative process, adopting an interpretive stance.

***Table 3.1*:** Inclusion and Exclusion criteria

Inclusion	Exclusion
English text	Non-UK based studies/ Non-English Text
UK based studies	Physiological aspects of diabetes/ Laboratory experiments using animals
Studies on Type 2 diabetes only	Type 1 diabetes
Self-care/management regimes – I.e. Diet, exercise, medication, SMBG	Morbidly/Mortality/Epidemiology/Prevalence
South Asian population	Pregnancy/Adolescents/Mental Health/Cognition/ Cardiovascular conditions
Qualitative	Poster Presentations/ Quantitative articles
	Theses

3.2.3. Selection process

The initial screening consisted of scanning article titles and abstracts to determine whether the studies were relevant to the aims of this review. The initial screening sought to assess if the article 1) described a qualitative research study and 2) focused on the target population (South Asian) and 3) explored experiences relating to T2D self-management (*Figure 3.1 for the outcome of search process*).

The initial search yielded 44 articles from this, 23 articles were removed as duplicates. The remaining 21 articles were subject to systematic screening: Seven articles were removed at the title stage, (three papers were of a non-UK sample, one paper was with a Black Caribbean sample, one paper focussed on heart disease and two were abstracts). At the abstract stage seven articles were removed (three articles explored non-self-management practices, three were on a non-UK sample, and one used a mixed sample and both Type 1 and Type 2 diabetes patients) (*Appendix 3.3 for a full list of excluded articles*).

Seven papers were retrieved from the initial database search and following further screening three of these articles were excluded (one was a thesis, one was a review, one explored other co-morbidities) leaving four articles to be included in the review (*Table 3.2 for article numbers: 4, 5, 7, & 8*).

Following the initial database search, Bates (1989) [1]"Berry Picking Model" was applied and an additional 13 articles were retrieved; one article (9) was found via a reference in Lucas, Murray and Kinra (2013), one article (3) was retrieved through the reference list of the included articles (8). One article a thesis (Macaden, 2009) was retrieved in the initial search, but following a search for the authors work, it was replaced with a published version (6). In addition, this search returned an additional article for inclusion by the same author (10). Database and internet search retrieved an additional nine articles (1, 2, 11, 12, 13, 14, 15, 16, & 17). In total, 17 articles were included in this review.

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[1] Berry Picking Model consists of 6 strategies (1. Footnote chasing, 2. Citation searching, 3. Journal run, 4. Area scanning, 5. Subject searches in bibliographies and abstracting and indexing service, 6. Author searching)

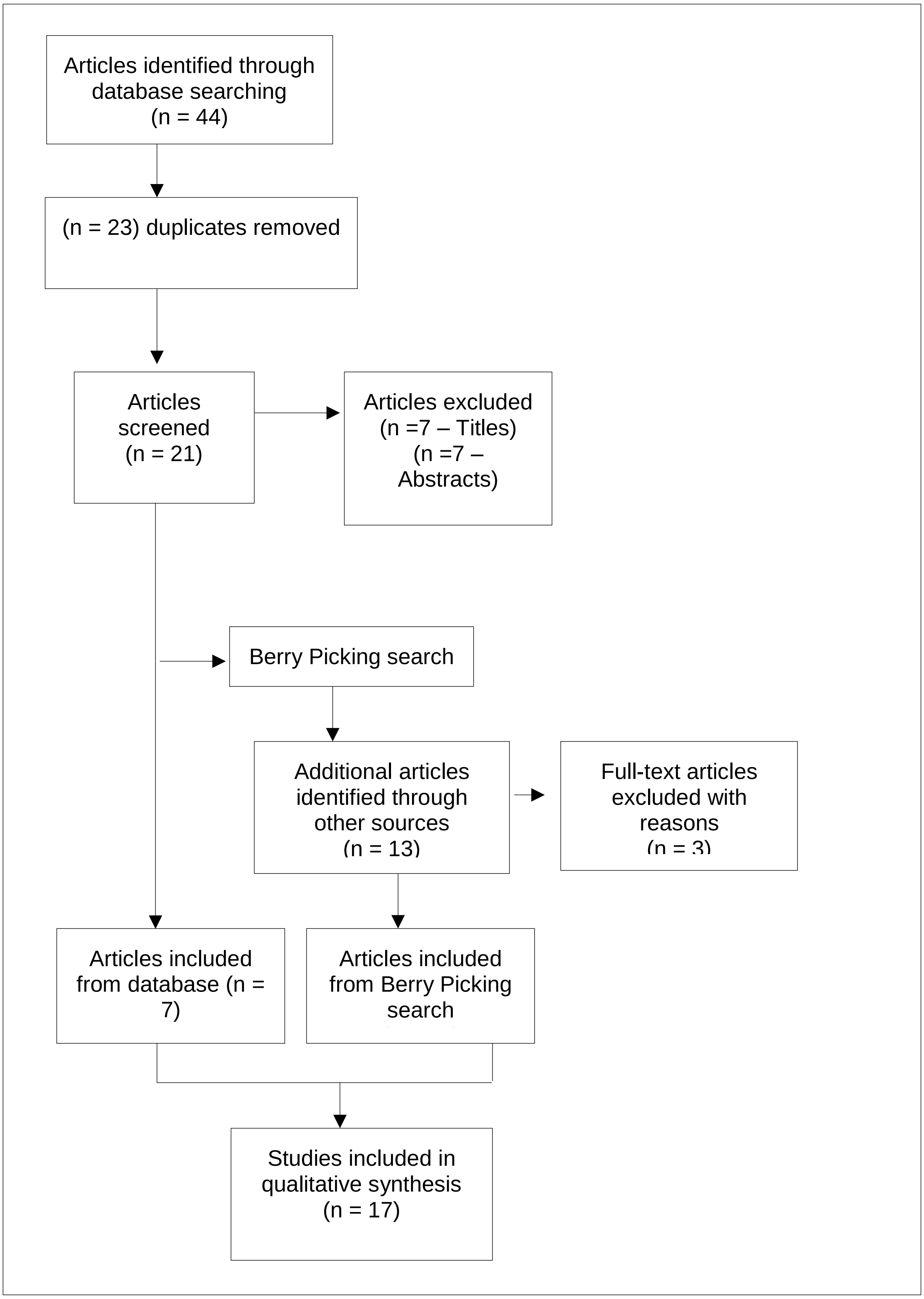

Figure 3.1: Outcome of the search process

Seventeen publications were identified and included (*Table 3.2 for study ID numbers*). The study numbers in this table are the identification numbers applied throughout this chapter and referred to in text via bracketed numbers, e.g. (1) refers directly to study number 1.

Table 3.2**:** Study numbers

Study ID Number	Author, Year of Publication
1	Khajuria and Thomas (1992)
2	Kelleher and Islam (1994)
3	Chowdhury, Helman, and Greenhalgh (2000)
4	Bissell, May and Noyce (2004)
5	Lawton, Ahmad, Hallowell, Hanna, and Douglas (2005)
6	Macden & Clarke (2006)
7	Lawton, Ahmad, Hanna, Douglas, and Hallowell (2006)
8	Lawton, Ahmad, Hanna, Douglas, Bains, and Hallowell (2008)
9	Choudhury, Brophy, and Williams (2009)
10	Macaden & Clarke (2010)
11	Jepson, Harris, Bowes, Robertson, Avan, and Sheikh (2012)
12	Gumbler (2014)
13	Majeed-Ariss, Jackson, Knapp, and Cheater (2015)
14	Fleming & Gilibrand (2009)
15	Greenhalgh, Helman, and Chowdhury (1998)
16	Duthie-Nurse (1998)
17	Patel & Iliffe (2016)

3.2.4. Data extraction, synthesis and critical appraisal

A data-extraction table (*Table 3.3*) was devised to assist in systematically identifying information for each of the 17 studies, this included: 1) Author, 2) Year of Publication, 3) Purpose/objectives, 4) Sample size, 5) Location, 6) Method of Data Collection, 7) Data Analysis, 8) Main results/key Findings.

Credibility, dependability, confirmability, transferability, authenticity, and relevance of the qualitative studies was evaluated using published tools

(Qualitative Research Quality Checklist, Saini, (2011); and Critical Appraisal Skills Programme, (2000)) to assist with these appraisals (*Appendix 3.4*). In line with CIS methodology, this process aimed to support the understanding of studies, as opposed to categorically scoring study quality. Data extraction and appraisal were completed by the researcher, a random sample of data extraction and study appraisal was also conducted by the other authors LN (n= 11), KU (n= 3), HP (n=3).

The research team discussed and reflected on the appraisal of studies, this information, in turn, informed the interpretation of the synthesis (Dixon-Woods et al., 2006). A thorough audit trail of team reflections, decisions, and meetings was recorded throughout. To maximise the inclusion of studies into the new synthesis, no studies were excluded from the CIS because of the outcome of the study appraisal (*Appendix 3.5: Full critical appraisal*).

3.3. Quality appraisal

Qualitative framework**.** All studies clearly stated the purpose and aims of the research to be conducted. The primary objectives of the studies were to explore the experiences of numerous self-management aspects of T2D in an SA sample. The qualitative approach was deemed appropriate to answer the questions because of the exploratory nature of the studies. Many of the studies did not clearly state their theoretical frameworks (1, 2, 4, 5, 6, 7, 8, 9, 12, 14, 17), of the studies that did report their frameworks these include; principles of anthropology (3); theoretical foundations drawn from

Symbolic Interactionism (10); sports sciences and public health perspectives (11); Identity Theory (13); Anthropological analysis (15); and Abu-Lughod (16).

Study setting. The setting of the studies was appropriate and specific for exploring the research question. Most studies interviewed participants at homes (4,12, 2, 5, 7, 8,14, 16), one study invited participants to attend an education session (9), one study conducted focus groups at a community centre and café (11), one study conducted face-to-face interviews in a GP practice (17) and four studies did not specify where data was collected (1, 6, 10, 13). Two studies did not clearly state where data was collected (2, 15).The studies did not engage prolonged engagement or persistent observations in the setting to respond to the research questions.

Study design*.* The research designs of the studies were deemed appropriate for the research questions.

Sample procedures. Overall, the sample selection was adequately described and consistent with the research design and questions of the studies. Sample selection took place predominately through diabetic clinics (1), health/ community centres (2, 11, 14) primary/secondary care (3, 4, 5, 6, 7, 8, 10,15,16, 17) word of mouth, asking local members of the community to part take and asking a local mosque to make announcements through radio transmitters (9, 12, 13). In line with the research design, purposeful sampling was employed across the studies. The sample sizes and composition are justified and appropriate to the research designs.

Data collection. Studies adequately describe their methods for data collection which predominately consisted of interviews (1, 2, 4, 5, 7, 8, 9, 10, 12, 13, 14, 16), two included focus groups (6, 11), five utilised a variety of qualitative methods observations, and interviews (1, 13, 14, 15, 17) and one also used observations (14). Triangulation of the data was not explicitly discussed by all studies, only in three articles (5, 7, 8). Issues related to validity and rigour were addressed at two levels (data and interdisciplinary) for two studies (6, 10). Reliability was considered by having the interview transcripts and recordings checked by translators who spoke Pakistani and Indian alongside the researcher (9). One study reported that three researchers compared the analytical themes created (11). Some of the studies clearly indicated who collected and analysed the data (e.g., principal investigator) (4, 5, 11, 10, 14, 16, 17). However, most of the studies did not indicate who was involved in the study and the length of time in the setting apart from (11, 5, 14, 17). Four studies indicated the use of an audit trail (e.g., audio-recordings, memo writing, researcher notes) (7, 8, 10, 11). Some of the studies.

Ethical issues. Overall ethical issues were poorly reported across the studies. A handful of studies (5, 7, 8, 9, 10, 11, 13, 14, 15, 17) mentioned relevant ethical issues and stated ethical approval had been sought. The other studies did not explicitly confirm ethical approval or highlight any ethical issues (1, 2, 3, 4, 6, 12, 16). However, prior to publication, the authors would have confirmed adherence to ethical standards as a requirement of the publishing journal.

Reflexivity of the researcher*.* Only three studies (4, 7, 10) discussed potential and actual biases within themselves as researchers and the research design. One study (14) briefly mentioned a possible source of bias from the participants who may have been offering an ‘ideal patient’ response. Most (1, 2, 3, 4, 5, 6, 8, 9, 11, 12, 13, 14, 15, 16, 17) did not report using a reflexive journal in the data collection or data analysis processes.

Data analysis*.* For analysis and interpretation: four primarily applied thematic analysis (9 & 11 (Fereday, Muir-Cochrane, 2006), 13 & 17 (Braun & Clarke, 2006); six used GT (5 & 8) Strauss & Corbin, (1990), (4 & 7) Glaser & Strauss (1967), (6 & 10) did not state which GT approach was adopted; two used anthropological analysis (15, 3) (Hall, 1977); one used topic and analytic coding (14) (Morse & Richards, 2002); five did not explicitly state the analysis (1, 2, 12, 15, 16). All studies apart from one (1) provided a wealth of quotations from the participants that were used, as evidence to match concepts and themes derived from the raw data.

Findings*.* Member-checking was applicable in all of the studies, although it was adequately addressed in only four (3, 5, 6, 10).

3.4. Analysis

3.4.1. Description of primary studies

It is noteworthy that of the 17 articles, a number of studies were ‘Salami sliced’ (Šupak Smolčić, 2013) into more than one publication. Specifically, articles (3 & 15) referred to the same empirical research although reported different research elements; this was also the case for articles (6 & 10). In addition, articles (5, 7 & 8) were also referring to one single empirical study. This was either explicitly acknowledged or cross-referenced (3, 15) or confirmed via correspondence with the authors of the papers (6 &10; 5, 7 & 8).

The studies covered a broad range of topic areas; 5 articles focused on diet (1, 2, 3, 8, 16); one on health care interactions (4); one on medication (5); two on risk perceptions (6, 10); two on PA (8, 11); four on self-management (9, 12, 13, 15); and two on health beliefs (14, 17). The included studies involved a total of 311 participants with T2D; 10 key informants (11); 35 close relatives (2, 15), seven practitioners and six health development workers (10).

The participant characteristics of the study samples varied across studies. The SA descent of participants was diverse: one article focused explicitly on Gujarati Muslim participants (15); three articles included only Indian (Gujarati) participants (1, 16, 17); four articles included only Bangladeshi participants (2, 3, 9, 14); two studies included only Pakistani participants (4, 13); three studies included both Pakistani and Indian participants (5, 7, 8), and four studies incorporated three SA descent (Bangladeshi, Indian, and Pakistani) participants populations (6, 10, 11, 12) . Four of the studies (5, 7, 8, 15) justified their chosen population cohorts by stating that the qualitative study was conducted in a specified language which therefore required the restriction of participant decent to those speaking said language.

The majority of studies (10) included both male and female participants (1, 2, 5-11, 17), one study recruited a male-only sample (15), three studies recruited a female only sample (12, 13, 16). However, three studies did not state the participant's gender (3, 4, 14).

All of the studies were conducted in the UK and published in English: four conducted in Scotland (5, 7, 8; 11); 11 in England (1 2, 3, 4, 6, 10, 12, 13, 14, 15, 16, 17) and one in both England and Wales (Birmingham or Swansea) (9).

Table 3.3: Summary of articles

Study ID Number	Author, Year of Publication	Purpose/objectives	Sample size	Location	Method of Data Collection	Data Analysis	Main results/Key Findings
1	Khajuria and Thomas (1992)	Explore the extent to which traditional beliefs about diet, health and diabetes, as described in the classics of Ayurvedic medicine, are held by Indian (Gujarati) diabetics in Britain.	28 Gujarati, Hindu, vegetarian, patients with diabetes	Diabetic clinics at two London Hospitals. (England)	Interviews	No clear indication as to which analysis was used, however, results are shown in themes	• Belief in traditional remedies and the role of food in the management of diabetes. • Traditional meal patterns, Patients eating habits. • Dietary advice received from the hospital
2	Kelleher & Islam (1994)	To understand and describe how Bangladeshi people with diabetes attempt to integrate traditional and religious rule-governed system of eating with the system of modern medicine.	40 Bangladeshi patients, 25 males and 15 females of varying ages. 30 family members	One health centre in the Tower Hamlets district. (England)	Interviews & Observations	Preliminary analysis on a selected sample of n=20, 12 men and 8 females. Unknown how the sample was selected for analysis.	• The development of self-help groups for Bangladeshi people will encourage them to talk about their experiences of diabetes and the treatment regimens in the contexts of their everyday Muslim lives.
3	Chowdhury et al. (2000)	Report on the food beliefs and classification system of British Bangladeshis.	40 informants with diabetes, all immigrants	Inner city areas of Tower Hamlets, Newham or Islington in	Audiotaped narrative, Semi-structured interviews, Focus groups,	Anthropological analysis. No quotes from participants as evidence.	• Primacy of religious prohibitions. • Ethnic dietary customs

			from the Sylhet region of Bangladesh	London. (England)	Construction of genogram, Pile sorting exercises, Structured vignette method, Feedback of preliminary constructs to focus groups, Study of patients' general practice case notes	Interpretative commentary with reference to the previous evidence base.	imported from Bangladesh. • Modification of diet on immigration to the UK: impact of availability and affordability. • Classification of food: strength and digestibility dimensions. • Digestibility dimension. • Strong-weak dimension. • Role of cooking in modifying edibility. • Food, health and illness.
4	Bissell et al. (2004)	Explore the relevance of a re-framed consultation with a small group of English speaking patients of Pakistani origin with a diagnosis of T2D	21 Pakistani origin participants	Two primary practices and one secondary care diabetes centre located in the north west of England.	Semi-structured interviews	Grounded theory (Glaser & Strauss, 1967).	• Themes identified: • Integrating the diabetic regimen, • Respondents' experiences of healthcare interactions
5	Lawton et al. (2005)	To explore British Pakistani and British Indian patients' perceptions and experiences of taking oral	32 patients of Pakistani and Indian origin with T2D,	Primary care and community sources in Edinburgh, Scotland.	An observational cross-sectional study using in-depth interviews in English or Punjabi.	Grounded theory	• Initial reactions to taking OHAs, • Perceptions of OHAs, Self-regulation of OHAs, • Self-regulation strategies

		hypoglycemic agents (OHAs).					
6	Macden & Clarke (2006)	Developed knowledge of the experiences of South Asian people with diabetes in the UK in relation to socio-cultural and dietary practices, religion and ageing influences on the perception and understanding of risks.	Ethnic health development workers, health professionals and 20 SA men and women with T2D	North East England.	Focus group interviews and one-to-one interviews	Grounded theory	• Factors influencing risk perception • Weighing up risks
7	Lawton et al. (2006)	Explore patient perceptions and experiences of undertaking PA as part of their diabetes care.	32 participants (Indian (n= 9) and Pakistani(n= 23)	Five general practises in Edinburgh. (Scotland)	Semi-structured interviews	Grounded theory (Strauss and Corbin 1990).	• Lack of time: obligations to others • Fear and shame • Lack of culturally sensitive facilities • Climatic conditions • Co-morbidities • Accounts of causation: perception of future health • Diabetes triggers an irreversible decline • PA can engender anxiety • Short term goals • I do enough already

8	Lawton et al. (2008)	To look at food and eating practices from the perspectives of Pakistanis and Indians with T2D, their perceptions of the barriers and facilitators to dietary change, and the social and cultural factors informing their accounts.	23 Pakistanis (22 Muslims, one Christian) and nine Indians (four Hindus, five Sikhs)	Five general practices in Edinburgh	Semi-structured interviews	Grounded theory (Strauss and Corbin 1990).	• Information from healthcare professionals • Perceptions of SA foods: bad for health; good for self • Settlement, sharing and commensality • Strategies for passing: cutting out or cutting
9	Choudhury et al. (2009)	Examine the understanding beliefs of people with T2Dfrom the Bangladeshi community living in the UK.	14 Bangladeshis	Swansea or Birmingham (Wales/England)	Structured Interviews	Theme analysis	• Cause of diabetes • Preventing diabetes • Diabetes diagnosis • Management of diabetes • Information from health care professionals • PA • Information from family⁄friends and use of traditional medication • Diabetes education
10	Macaden & Clarke (2010)	To analyse risk perception among older SA people with T2Din the UK.	Ten Health development workers, seven individual interviews	North East of England.	Two focus group interviews with health development workers, seven	Grounded theory with its theoretical foundations drawn from Symbolic	• Perceptions of External Responsibility • Perceptions of internal responsibility

			with practitioners (three physicians, three nurse specialists and a dietitian); 20 interviews with UK-resident older SAs (nine men and eleven women) with T2D		individual interviews with practitioners	Interactionism.	• Control and influence
11	Jepson et al. (2012)	Explore the barriers, motivators and facilitators to SA adults undertaking PA, with the broader aim of guiding the development of future interventions and services.	59 Bangladeshi, Indian and Pakistani participants 10 Key Informants	Urban areas of Scotland, Aberdeen, Glasgow and Edinburgh.	Focus group discussions with participants and semi-structured interviews with key informants,	Thematic analysis (Fereday, Muir-Cochrane, 2006)	• Types of PA people engaged in • Social interaction • Enjoyment of exercise • Mental and physical benefits • Leadership and role models
12	Gumbler (2014)	investigate whether there was a knowledge gap among SA women with T2D about diabetes development and management.	Six SA women	Warwickshire or in Birmingham	semi-structured interviews	No clear indication as to which analysis was used, however, results are shown in themes	• Diabetes knowledge • Diet • Physical inactivity and a healthy lifestyle • English fluency and language barriers

							• Potential improvements to the NHS • Other findings
13	Majeed-Ariss et al. (2015)	To explore the effects of T2Don British-Pakistani Women's identity and its relationship with self-management.	15 British-Pakistani women with T2D.	Teesside, England	Face-to-face semi-structured English and Urdu language interviews	Thematic analysis	• Perceived change in self-emphasised how British • Familiarity with ill health reflected women's adjustment to their changed identity over time; • Diagnosis improves social support enabled women to accept changes within themselves • The over-arching theme Role re-alignment enables
14	Fleming & Gilibrand (2009)	To present the findings of a study which explored the influence of culture on (type 2) diabetes self-management in Gujarati Muslim men who reside in northwest England.	5 Gujarati Muslim men	Northwest England	A case-study approach	Topic and analytic coding	The findings highlight that the complexity of life means that culture never exists in isolation but is one of the many factors that a man negotiates to inform his diabetes self-management.

15	Greenhalgh, et al. (1998)	To explore the experience of diabetes in British Bangladeshis, since successful management of diabetes requires attention not just to observable behaviour but to the underlying attitudes and belief systems which drive that behaviour.	40 British Bangladeshi patients	Three general practices in East London	• Audiotaped narrative • Semi-structured interview • Focus group discussion • Construction of genogram • Pile sorting exercises • Structured vignette method • Feedback of preliminary constructs to focus groups • Study of patients' general practice case notes	No clear indication as to which analysis was used	• Body concept • Origin and nature of diabetes • Impact of diabetes • Diet and nutrition • Smoking • Concept of balance • Exercise • Professional roles • Diabetic monitoring
16	Duthie-Nurse (1998)	The patients' views of illness and how it was treated, with particular regard to diet	20 Hindu SA women	Diabetes Clinic, St Georges Hospital, South West London	Open and closed-ended interviews	No clear indication as to which analysis was used	• Consciousness of health and disease • Duties of sick women towards household and gods • Emotional stress, followed by 'recharging' through visits to family in India (and America)

							• Objective assessment of interplay between environment and disease • Displacement and alienation as factors actively influencing the foregoing.
17	Patel & Iliffe (2016)	To explore the influence of health beliefs and behaviours on diabetes management in British Indians, as successful management of diabetes is dependent on underlying cultural beliefs and behaviours.	10 British Indians	General Practice in North West London	• Semi-structured interviews • Pile sorting exercise	Thematic analysis	• Causal beliefs about diabetes • Adaptation of exercise • Use of alternative therapies • Modification of diet • Sources of information

3.4.2. Analytical procedure

To produce a new synthesising argument (line of argument), the CIS analytical procedure was informed by that undertaken in primary qualitative research (e.g. grounded theory, Strauss & Corbin, 1990). A detailed inspection of the papers, focusing on the analytical findings and discussion section of articles, followed by coding (279 open codes) (*Appendix 3.6*), generating synthetic constructs (26 axial codes (*Appendix 3.7*) with various supporting memos (*Appendix 3.8*) compared across studies, to generate a new theoretical framework was completed (*Figure 3.2*).

3.4.3. Synthetic model of results

The CIS analysis of these studies provided rich findings concerning how the patient's cultural identity creates conflict. The synthesising argument revealed two core synthetic constructs; cultural identity and decisional conflict characterised by three second-order constructs; daily lifestyle/ roles influence behaviour; doctor-patient relationship and beliefs and implementation; leading to the defensive avoidance as an outcome in self-management behaviours.

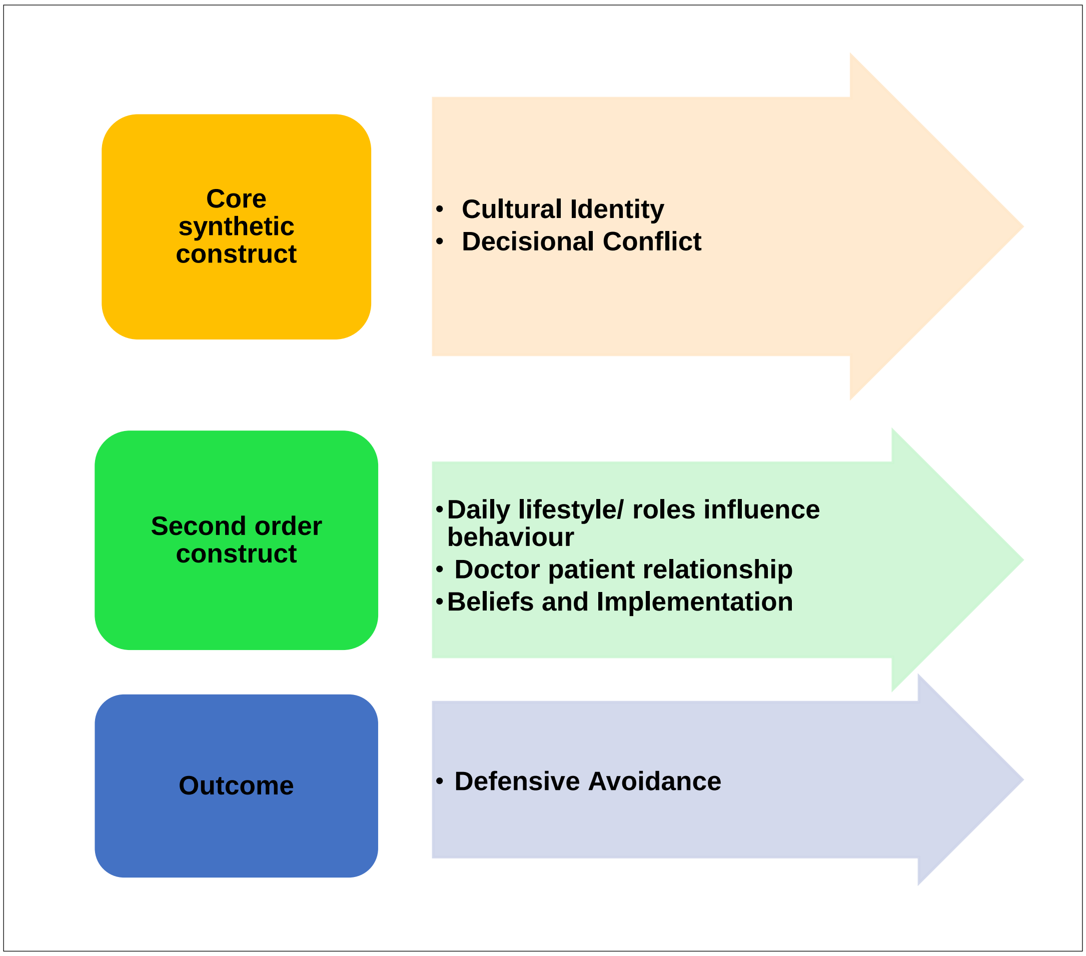

Figure 3.2: Model of cultural-versus-health conflicts

Core synthetic construct: Cultural Identity

A diverse ethnic and religious background was reported within the studies, most participants had originated from their (home) country of origin and held their cultural identity as very important to them. Their cultural identity influenced dietary habits, thus significantly affecting patient’s diabetes self-management as they were reluctant to detach from their cultural dietary behaviours. For example, the SA traditional breakfast comprised strong, thick cup of tea with milk and sugar with biscuits (3). The typical lunch and dinner meals consisted of chapati, curried vegetables, dahl and rice (1, 12), considered as key staples in the patient's everyday diets compared to the traditional UK diet, such as toast, jam, pizza and noodles, which were rarely found in the SA homes (1, 3). Equally, there have been changes in food practices due to the availability of foods in the UK, which have been adapted to the SA diet (3).

Comparisons were made between ‘them’ (being people of non-SA origin), and ‘us’. ‘Them’ being white Caucasians specifically referred to as ‘goray’. SA perceive ‘goray’ to suffer from T2D less frequently than the SA population (8). They categorised ‘goray’ food as bland and tasteless compared to SA curries, rice and chapattis. Not eating SA cultural food, was suggested to be detaching themselves from their SA culture (1, 8). Taste and flavour were important to the SA population, and the use of oil and ghee were considered essential ingredients used in cooking methods (3, 8, 12, 14, 17). Although alternate ways of cooking, e.g. boiled, baked and grilled were acknowledged, there was hesitation to change methods of cooking (3, 8, 12). Certain foods were perceived to be better for the body if they were cooked in certain culturally adapted way (3).

Core synthetic construct: Decisional Conflict

It is possible to resolve conflict, in relation to cultural identity, by health professionals acknowledging the SA patients’ cultural needs and attitudes towards diet (1, 3, 8). For example, it could be mitigated by educating SA patients on culturally-appropriate healthy eating practices (1, 8, 16).

Self-management of T2D created conflict between health professionals and SA patients due to patients feeling that there was little acknowledgement of their cultural relevance and specific needs. Culture conflict was described as causing social offence and not part taking in social gatherings as they felt they were being judged (6). Motivation such as family support was particularly important to effective self-management behaviours (especially those relating to dietary behaviour) helped patients take responsibility (10, 13, 17). Studies suggested various contributing factors, which facilitated this conflict with a patient's culture, such as cutting down on staple dietary foods, which include chapatti and rice. These foods hold significance to SA culture and suggesting a change in food consumption creates conflict when making choices to their T2D self-management (1, 6, 7, 9, 10, 12). When this conflict was resolved, and the patients were able to accept their T2D as a priority behaviour, they were able to make adaptable changes to their lifestyle, in-line with diabetes advice and hence improve their self-management behaviours (1, 6, 7, 8, 11, 10, 13).

However, across studies patients had a lack of understanding towards T2D (1, 3, 6, 7, 9, 12, 14, 17), specifically accepting the medical cause for the onset of diabetes (3, 9, 12, 14). Some patient beliefs regarding T2D causation included factors outside of their immediate control such as; stressful events and worry (1, 6, 12, 14, 17) and the will of God (6, 7). These beliefs influenced patients understanding of T2D prevention and management strategies (9, 8, 10). Such perceptions were formed and affected by the information received from health professionals (9, 8).

Second order construct: Doctor-patient relationship

Health professionals were reported to play a vital role in patients diabetes care (5, 9, 10). Health professional's advice and prescriptive recommendations were perceived to be outside of a patient’s control and hence at times patients reported helplessness (10). Strong cultural values extended to the doctor-patient relationship; this is a crucial aspect to consider, as it is essential to understand the most effective ways to deliver personalised patient-centered care. Relationships with the health professional were based on respect, as patients considered the health professional as the expert, and would not feel comfortable to challenge the advice they received. However, across studies, various aspects of misunderstanding health professional advice were apparent (4, 2, 8, 14).

Language has been identified as a barrier towards effective clinical communication. It was reported that (foreign) language was an obstacle for patient interaction with health professionals (9, 12, 14, 17). Having language translators or an interpreter during consultations was suggested to eliminate communication difficulties. Although it was reported that translators helped to understand basic information. However, it was acknowledged that this approach limited interactions and exploration of questions. Patients felt unable to comprehensively address all the issues and uncertainty held (perhaps due to time limitations as interpretation extended the consultation process or perhaps due to the patient receiving basic information from the interpreter but not having the confidence to ask questions themselves) (9, 14).

However, the synthesis suggests (foreign) language translation was just one aspect that reduced effective communication between the health professional and patient. The analysis indicates that T2D and lifestyle terminology used by health professionals during consultations was challenging to understand, regardless of language spoken (1, 8, 9). Terms such as ‘dieting’ and ‘diet-control’ have been poorly understood (8, 9, 12). For example, diet control was assumed to focus on ‘sugar’ intake only (9). It was reported that information was best understood if it was received from a doctor who was able to convey messages in the SA mother tongue (9, 15).

There was some awareness of ‘bad eating habits’ and the effects it may have. However, certain foods were considered part of SA culture and helped define their identity, which was difficult to let go of or adjust for the purposes of health conditions such as T2D (2, 8). Although dietary advice was received and understood, generally the participants reported that the information was basic and generic with no culture-specific advice regarding meals which could be adapted to their SA lifestyle, which caused confusion (1, 2, 3, 4, 8, 9, 12).

Second order construct: Beliefs and implementations

Religious beliefs were found to influence self-management, such as ‘*informing food choices’*. This to be specifically pertinent to the patients aligned with Muslim religion (3). Muslims slaughter animals in a set method before they can eat it, this is known as ‘Halal’ (blessed food) (Riaz & Chaudry, 2004). Other foods are forbidden and referred to as ‘Haram’ (e.g. pig products and alcohol) (Soon, Chandia & Regenstein 2017). Although some do not actively practise religious routines, such as attending mosque regularly. Adhering to rules relevant to food intake, e.g. halal and haram, was a pertinent compliant behaviour, and non-negotiable, although typically reported as not acknowledged by health professionals (3).

Religious beliefs influenced self-management through additional '*religious obligations'.* For example, for patients who were from the Sikh religion, explained that the Sikh Temple held weekly meals serving traditional Sikh foods, such as chapatti and curries. Patients reported awareness of the ingredients and cooking methods used in these meals and acknowledged the possible subsequent negative effects such foods may have on blood glucose levels (affecting T2D management). However, the food was deemed 'essential' to consume, as it would be disrespectful not to participate (8).

Religious obligations, such as fasting, appeared to supersede T2D responsibilities. For example, Hindus reported 'fasting for God' as a priority rather than dietary influences on their diabetes (16). For Muslims, fasting periods were compulsory elements to demonstrate adherence to religion. For example, the participation in Ramadan (30-day fasting period). However, if a person were, for example, pregnant or had an illness, they may be legitimately exempt from fasting behaviour (3, 6, 8). This practice was however controversial, and for some with diabetes, they did not consider T2D as an illness, to exempt them from fasting behaviour. Fasting behaviour can have a significant impact on T2D management, and patients may not have sought medical advice, or indeed not informed their health professional of their intention to take part in such prolonged fasting behaviour. Moreover, some patients acknowledged that they might have amended their medication intake (oral medication may be considered a food source), again without medical consultation (3, 5, 6, 8).

Participants from different religious backgrounds reported varying beliefs regarding PA. For example, an enjoyment in Bollywood and Bhangra dancing was highlighted, for some SA participants. However, bhangra dancing is explicitly linked to the Sikh religion (Schreffler, 2013), and the Muslim religion does not permit listening to music or dancing (Nasr, 1976). Thus, health professionals should be mindful of these religious nuances when recommending PA, which has music associated with it (11), as doing so may disengage or even cause offence to some SA patient groups.

Perceptions about future health influenced patients acceptance of T2D. For example, the acceptance that ageing made illness unavoidable and thus uncontrollable (6, 7, 14). These beliefs were made by patients comparing themselves to older members of their SA communities. Moreover, a misperception that going home to ‘India’ would ‘cure’ their diabetes as T2D was attributed to patient’s external locus of control (environmental factors such as living in London), rather than accepting personal responsibility for their diabetes and engaging with their internal locus of control (e.g. power to change dietary and exercise habits) (10, 14, 16).

An overall lack of understanding leads to creating short-term goals instead of prioritising long-term health (6, 7). For example, deciding to engage in PA, may be an attempt at lifestyle change following a risk of being placed on insulin. The patient who has a fear (avoidance strategy) for using needles (insulin) may result in an attempt to make clinical improvement to engage in PA. However, these patients did not typically participate in PA for long-term T2D management per se, but as a fear defence tactic (7). Health beliefs were influenced by cultural perceptions, across SA communities it is regarded as a stigma to have health conditions such as T2D. Engaging in an observable physical behaviour such using insulin injections would have a negative influence on individuals, evaluation of themselves, as well as their community/social evaluation of them (6, 7).

For the majority of patients, T2D was managed (initially) via lifestyle management only. However, SA patients reported initial apprehension about taking T2D medication. Prescription medication (e.g. metformin) was thought of as unnecessary or could aggravate their health further or may confirm their role as a ‘sick person’ (5). Additional beliefs surrounding T2D medication were evident across the analysis: such as perceiving it to be detrimental to their health, only taking prescriptions for instant relief (such as when recognising their blood glucose readings were ‘high’), forgetting or not prioritising medication, misunderstanding side effects/ symptoms (e.g. taking ALL medications if ‘blood glucose reading was high’) and perceiving diabetes as an onset for other conditions (5, 13). Overall, there was an important acceptance of the role of T2D medication. However, it was reported that self-adjusting dosage, without seeking medical advice was common practice for patients. Often patients did not seek medical advice and such behaviour could occur over an extended period and never raised with their health professional (5).

SA patients had traditional values associated with individual foods and dietary behaviour. Traditional foods considered as ‘strengthening and fortifying’, which were thought to balance out the potential side effects of T2D medication. These misconceptions have been endorsed by the SA countries where taking medication is perceived to have long-term damaging effects if taken over a long time (3, 5, 6, 14). Social and cultural roles played a significant part in an SA’s lifestyles (1, 6, 7, 8, 10, 13, 14, 15, 16). Frequent attendance at social gatherings, events and part-taking in a number of festivals, (such as Eid for Muslims, Diwali for Hindus and Sikhs) was deemed as an important aspect part of lifestyle (1, 6, 7, 8, 10, 13, 14, 16). At these events, meals would be served, consisting of foods high in fat, sugar, salt and low in fibre (1, 6, 7, 8, 10, 13, 16). Despite being aware of the effects of consuming such foods. Individuals felt obliged to abide by cultural expectations, and would, therefore, consume such foods. This cultural-social activity would be prioritised over and above their needs to consider their T2d self-management behaviours (1, 6, 7, 8, 10, 13, 14, 15, 16). Refusal to eat such foods or consuming their own foods at social and special events would be deemed disrespectful and offend (1, 3, 6, 7, 8, 10, 13). Typically, patients had a lack of awareness of being able to make a connection between T2D management and specific dietary behaviour (3, 5, 8, 12). Typically, diet was considered only in relatively simple terms such as reducing intake of traditional sweets and dietary foods such as ‘roti’ (9, 8, 10), although often complete ‘meals’ were not evaluated in the same way.

Another aspect of diabetes self-management that was influenced by culture was the use of alternative medicines which was found to be prominent in SA participants (1, 5, 9, 13, 15, 17). The acceptance of using alternative medicines has been influenced by their culture within their country of descent (‘home country’) (15). Many perceived that the alternative medicines were more effective than (Western) prescribed medicine (1, 5, 9, 13, 15), and this was not something that was discussed during health care consultations. For example, food items such as Karela (the most popular), Guar, Tindoora and Methi leaves were considered to aid glucose control, if eaten regularly, and it was reported that SA patients used these foods as therapeutic agents (1, 9, 13, 17). The explanation of the effectiveness of such therapeutic agents was attributed to the foods bitterness, making the blood thin and balancing the sugar in the body (1, 5, 9, 13, 17). Khajuria and Thomas’s (1992) study reported that a participant ingested Karela juice the day before a hospital appointment in an attempt to lower blood glucose levels and hence show better control. It was reported that advice from family and friends encouraged patients to take these alternative medicines (regardless of the taste) because they believed them to be more effective than traditional prescription medicines (9, 13). This also highlights the role of cultural pressure from family members which may influence T2D self-management behaviours.

Despite broad acceptance of alternative medicines across patients in these studies. Some believed that advice from health professionals was sufficient and there was no need to take alternative herbal medicines. Some acknowledged that UK health professionals were trustworthy prescribers (they had no financial gain compared to their health professionals in their home countries where they had to pay for care) (5, 13, 15).

Second order construct: Daily lifestyle/ roles influence behaviour

Dietary behaviour was particularly problematic for women. SA Women were considered responsible for family cooking (4, 6, 7, 12, 13, 14, 15). Even though the female participants reported attempting to integrate healthy options into their family meals (e.g. by separating out individual portions before adding sugar) (8). Family preferences and adherence to traditional cooking meals and cultural foods took priority before implementing specific dietary advice to support diabetes management (4, 6, 13). Males rarely acknowledged input in family meal preparations (4, 8, 14) thus often their food consumption was determined by another (wife/ mother/ daughter).

Perceptions of consumption of fruit and vegetables differed compared to the recommended National Guidelines (Public Health England, 2016), with patients reporting fruit and vegetable would increase glucose levels and thus have a detrimental impact on their T2D (12). Often patients reported high blood glucose levels; they made choices such as, not eating but only drinking to bring their glucose levels down and/or take less medication (5, 8).

SA patients reflected on the role of exercise and did not consider this as a cultural norm (4, 7, 8). In particular, SA women reported to stay at home and cited issues with the familiarity of the local area and fear of going out due to ‘bad experiences’ related to their T2D, e.g. passing out in public and being negatively judged by others (7, 8). Social explanations were also reported to influence women in not taking part in PA (4, 7, 13), such as lack of time, working anti-social hours, other household responsibilities, not being able to find single-sex exercise classes, and specific difficulties regarding racial harassment (7, 12, 13, 16, 17). SA women had a strong sense of family commitment and often prioritised the needs of the family prior to their own health needs. Taking ‘time-out’ to engage in PA was considered ‘selfish’ (7).

In order to be given ‘permission’ to engage in PA, patients sought endorsement or encouragement from significant others, for example, if religious centres promoted PA, it might become more acceptable to partake (11, 17). Enjoyment of exercise was found to be a motivating factor particularly when it included a social element (such as including friends) and was culturally acceptable (11). Positive gratification was reported as a motivating factor to engage in PA (7).

Family dynamics were important, and females have different cultural roles within the family to which they need to adhere to. Overall, women were found to have a lack of family support and their responsibilities often hindered their T2D management (4, 6, 7, 8, 12, 13, 15). The ‘women’s role’ was typical to stay at home, cook, clean, and take responsibility for the children (4, 6, 7, 12, 13, 14, 15). Although social events with families were common, taking part in family-based PA was not practical (12).

Outcome: Defensive Avoidance – Reconstruction of Knowledge

In conclusion, the two core synthetic constructs cultural identity and decisional conflict, together with the three second-order constructs of daily lifestyle/roles influence behaviour, doctor-patient relationship and beliefs and implementation, collectively these constructs are referred to in this new framework as defensive avoidance. Ultimately, suggesting that SA patients face conflict aligning to their cultural identity versus engaging with medical advice to change their lifestyle behaviour. To resolve such conflict, participants reported re-negotiating their cultural acceptance and thus engaged in the T2D behaviour, or they did not accept the medical advice and thus allowed their cultural identity to supersede T2D as a priority. Hence their lifestyle behaviour did not change (was not in line with T2D advice).

3.5. Discussion

This meta-synthesis (CIS) reviewed qualitative evidence and presented a reanalysis and reconstructed in-depth synthesis of the previous research evidence to portray a new understanding of the key issues and difficulties relating to adherence to T2D self-management behaviours within the UK SA population.

The CIS framework suggests that SA participants hold on to their identity in terms of their cultural habits, which play an important role in engagements with their daily lifestyle. The link between the concept of identity and self-management is that health professional advice appears to create internal (decisional) conflicts for these SA individuals. These conflicts if not managed well, interfere (often negatively) with their T2D self-management.

Conflict Theory (Janis & Mann, 1977) explains how people cope with the dilemmas of decision-making. Decisional conflict refers to a person's reaction when deciding whether to accept or reject an action. Symptoms include hesitation, emotional distress and feelings of uncertainty. Janis & Mann (1977) distinguished five basic patterns of coping behaviour that affect the quality of decision making: vigilance, unconflicted adherence, unconflicted change, defensive avoidance, and escaping conflict by procrastinating.

Considering these barriers, which offer insight into patient perspectives, however, managing the patient's internal conflict can create enablers which the previous evidence base has mentioned but has further explored. For example, previous research has highlighted that SA patients prefer culturally sensitive advice or facilities. However, there is an over-focus on identifying these issues but no practical solutions to overcome them.

The evidence base around T2D management is not necessarily being transferred on how to manage problems and or specific enablers to help manage diabetes. For example, research has acknowledged the issue of being offensive (8). However, it is not clear if it is explained to the patient that the situation can minimise the impact by reducing the portion size. Utilising insight can help the patient manage the conflict to rectify any issues in relation to cultural identity and diabetes self-management behaviours.

The findings of this CIS suggest that participants cultural needs were deemed more important than their health needs; conflict was managed through defensive avoidance by prioritising cultural lifestyles rather than health management and advice. Participants compared and prioritised lifestyle behaviours which superseded health (T2D) behaviours. For example, religious beliefs overpowered diabetes management as patients reported that having diabetes was the will of God, so they had no control of their condition (6, 7). Accepting diabetes as Gods will meaning they were helplessness in long-term outcomes of their T2D. Thus, any changes made in their behaviour towards self-management would ultimately have no impact, so the participants used this as an explanation not to engage in the recommended self-management behaviours. This is important to highlight, as current NHS provision promoting T2D education, may not be addressing these patient beliefs (such as T2D is caused and influenced by the will of God and sense of helplessness). The synthesis suggests that by current healthcare services not exploring a personalised approach, (which allows individuals to fully express and explore their lifestyle, cultural and religious beliefs) appears to prevent the patient from successfully managing their T2D behaviours.

The studies included within this CIS referred to patients throughout as SA. However, the heterogeneous nature of the SA population was overlooked or simplified. Some studies (4, 5, 7, 8 &14) did acknowledge limitations in the SA sample recruited; such limitations mainly occurred as a result of logistical research issues such as including participants based on ability to speak English (or other restricted SA languages). None of the studies acknowledge the complete heterogeneous nature of the SA population in the UK. However together this CIS brought together participants across a range of studies and thus the reanalysis and reconstruction were able to develop a more realistic and heterogeneous consideration of the SA population experiences of T2D self-management behaviours, as a whole SA group. Moreover, none of the original studies considered religious barriers directly in their analysis, although collectively in this CIS religious beliefs and behaviours appeared consistently throughout the reconstructed findings.

Previous research suggests that the SA population have preconceived ideas of how health care systems should work due to their experiences they had in their host countries e.g. as they pay for treatment they expect the best care which conflicts with their experiences with the western health care system which is a free service where you seek advice and listen to the expert. These historic view points and perceptions influence engagement of their care leading not to comply with recommended guidance (2, 4, 5, 9, 14).

SA historically use herbal remedies (such as kerela, methi seeds), however in the UK such remedies are not acknowledged (medicine regulation in the UK and herbal remedies are not included within this so not prescribed or recommended (Barnes, 2003; Vickers, Jolly & Greenfield, 2006)) leading the SA population to feel dismissed as family members regard them as a useful method of medication to overcome illnesses. This can lead to conflict as they do not feel they openly discuss these herbal remedies with their health professional which can then subsequently impact on their diabetes self-management (5, 13, 15).

This is the first review to deconstruct and reconstruct qualitative studies to create a new understanding of the issues facing SA patients with T2D conducting self-management behaviours. Previous qualitative research has presented an analysis of patients understanding, although these have not explored the patient’s experiences and considered findings from a health psychology perspective. For example, the two previous reviews (Fleming & Gillibrand, 2009; Sohal, Sohal, King-Shier & Khan, 2015) were not psychological, but the authors were from nursing and public health disciplines. These reviews did not account or explain self-management behaviours from a health psychology perspective (e.g. cognitive beliefs, perceptions and experiences) and thus the analysis in these previous reviews is somewhat limited.

3.5.1. Future Research

Findings from this CIS are particularly important regarding future research. This synthesis highlighted that most of the previous research identified has focussed on barriers and enablers to T2D self-management. Future research should explore the practical application of proactive ways to facilitate the facilitators that could help the SA population better self-manage. The next step for this PhD considered what were health professionals' beliefs, experiences and attitudes to T2D self-management is SA population (*Study 1; Chapter 5*); followed by; what were the patient's beliefs, experiences and attitudes? (*Study 2; Chapter 6*) moreover, what were family and friends' beliefs, experiences and attitudes (*Study 3; Chapter 7*).

3.5.2. Limitations

This synthesis highlights the previous research that has been carried out. This CIS was completed on the information (data) reported in the articles (or published supplementary files). Thus, there is a possibility that some information may not have been available for analysis. Nonetheless, the process of CIS was to reconstruct a comprehensive synthesis, and this has been presented.

3.5.3. Conclusion

Based on the CIS it is suggestive that perhaps SA needs are not being met and would be useful to understand what health professionals think about this as a concept, or what is being done to address the diversity of SA patients cultural and religious needs. This CIS presents a new theoretical framework to understand SA patient’s management and prioritisation of conflict behaviours, as determined and influenced by their cultural identity. Managing this decisional conflict can be considered a form of coping to justify their chosen lifestyle behaviours, which either positively or negatively influence their T2D management.

Part B

Chapter 4 – Overview of methodological approached applied throughout PhD

Chapters 5, 6, and 7: Qualitative studies exploring adherence to diabetes self-management.

A series of qualitative studies utilised interviews with a range of participants, including people withT2D, health professionals who support these patients, and family and friends of patients with T2D. The focus of the interviews originated from the issues identified from the Part A (specifically the meta-synthesis).

Chapter 5 - Study 1 – 'A qualitative study investigating health professionals' perceptions and experiences of supporting T2D self-management in SA patients'.

Chapter 6 - Study 2 – 'A qualitative study exploring cultural factors in T2D self-management amongst SA patients'.

Chapter 7 - Study 3 – 'A qualitative study exploring the experience, attitudes and views of family members involved in the care of SA people with T2D'.

Chapter 4: Methodology

Methodology - Chapter overview

This chapter presents an overview and justification of the methodological approaches adopted across the three following qualitative GT studies, (in addition individual study chapters (5, 6, 7) subsequently highlight specific methodological issues unique to that study).

4.1. Qualitative research

According to Creswell (2014), qualitative research has been described as “…the meaning individuals or groups ascribe to a social or human problem…” (p.4). The general framework of qualitative research is to explore phenomena, qualitative researchers incorporate an iterative process of data collection, which needs to be adjusted alongside what is being learnt from the participant. An iterative process can be achieved by using open-ended methods such as interviews, which can explore differences, experiences and explain relationships.

Qualitative research aims to gather rich and holistic data by utilising an open research process. Its focus lies in answering the questions about the why and how (Glenn, 2010). This PhD refers to Cresswell's (1998) definition: "A qualitative study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting" (p.15).

4.2. Philosophical assumptions and research paradigms underlying this research

Models of understanding recognised as paradigms support research. Paradigms guide decisions and research process (*Table 4.1*). Filstead (1979) defined a paradigm as a “set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organised study of that world" (p.34). It is essential to be clear which paradigm is being followed as it guides the researcher in the philosophical assumptions about the research and the methodology (Denzin & Lincoln, 2011).

Employing qualitative methodology was considered most appropriate for this PhD, as the best way to explore the issues and experiences around T2D self-management behaviours. From looking at the philosophical stances, the interpretivist view was deemed most appropriate for this research, as the aim was to understand people perspectives viewpoints and the reality of the situation. As the SA population are diverse in culture, ethnicity and religion, it was, therefore, important to take an interpretivist stance.

Table 4.1: Overview of paradigms

	Paradigms			
		Positivism-Quantitative	**Interpretivism-Qualitative**	Critical- Post-Modern – Mixed methods
Philosophy	Ontological	Realism	**Relativism**	Historical realism
	Epistemology	Objectivism	**Subjectivism**	Transactional and subjective
	Methodology	Experimental/ manipulative	**Dialectic and hermeneutic**	Ideology critique, action research and critical ethnography
	Methods	Quantitative Methods, i.e. questionnaires	**Interpretive approach i.e. interviews**	Mixed methods

Prior to selecting a chosen methodology for this research, it was essential to have an understanding of the philosophical paradigms and assumptions underpinning qualitative research (*Table 4.1*):

4.2.1. Ontology

The study of the nature of reality (Ramey & Grubb 2009). Greener (2011) described the ontological perspective as "about issues such as whether the world exists independently of your perceptions of it. According to Burr (2003), ontological theories fall into one of two opposing classifications realism and relativism. Realism is where the researcher sees the topic as external and independent from reality, therefore, taking a quantitative approach to conducting measurable studies. Whereas, relativism is based on whether the researcher sees the topic as a built reality based on individual experiences which allow the researcher to utilise a qualitative or mixed-methods approach which covers an individual and explanatory study. The ontological perspective of this research was based on relativism, as the studies explored individual experiences specifically for this research as people who self-manage face individual experiences and would differ from others who have T2D.

4.2.2. Epistemology

The philosophical position of the study of knowledge (Carter & Little 2007). According to Schmidt (2001), we can determine what is meant by knowledge in two ways. We can first identify the distinguishing characteristics of knowledge. Secondly, we can examine how people use the term what meaning it has for them and how the term knowledge subsequently influences their behaviour. Oliver (2010) defined it as "the grounds upon which we believe something to be true". As the researcher worked with the participants and continually reflected on the interpretation to access in-depth meanings of their experiences by prompting the participants to express themselves. This perspective was appropriate exploring the perceptions of individual experiences subjective of those who have T2D would allow to better understand experiences in diabetes self-management.

4.2.3. Methodology

Methodology looks at the research design and uses appropriate approaches to reach the answers to the research question (Denzin & Lincoln 2008; Guba, 1990; Punch, 2013). The interpretivist paradigm can be seen as an alternative to the positivist paradigm. Interpretivist posits a relativist position, which undertakes multiple valid realities (Schwandt, 1994). An interpretivist claim that reality is built in the mind of the individual rather than externally (Hansen, 2004). Interpretivist adopts a hermeneutical approach, which claims that meaning is hidden and must be brought to the surface through deep reflection (Schwandt, 2000). The interactive researcher–participant dialogue can inspire reflection; through interaction which can reveal the deeper meaning of the phenomena. The researcher and participants work together to construct findings from their interactive discussion and interpretation. The interpretivist researcher depends on the participant's responses (Creswell, 2003). Interpretivist "generate or inductively develop a theory or pattern of meanings" (Creswell, 2003, p.9). The interpretivist paradigm suggests that it is essential for the researcher to be part of all the phases in the process of the research to ensure there is no separation of subject and object. Truth is exchanged over dialogue. Interpretations are created at that exact moment and are located in a particular context. Interpretivism goals are idiographic and emic.

4.3. Qualitative approaches

There are many qualitative approaches; (*Table 4.2*). Therefore, it was important to identify which approach was most suitable for the research question in line with the purpose of the qualitative research, the role of the researcher, the stages of research, and the method of data analysis (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa, & Varpio, 2015; Wright, O'Brien, Nimmon, Law, & Mylopoulos, 2016).

Table 4.2: Overview of qualitative approaches

Approaches	Purpose	Approaches	Benefits	Limitations
Grounded Theory	Study of patterns and processes in human interactions	• Systematic procedures • Constructivist approach	• Provides novel evidence on under-researched areas • Development of theory from findings	• Time-consuming process • Can have methodological errors
Narrative study	Collection of individual experiences and stories	• Temporality • Sociality • Place	• Participants can express freely • Authorise participants experiences	• Researcher has to be clear about the participant's events as lived and the events as told • Unsuitable for large numbers of participants
Ethnography	Study of a whole culture	• Realist ethnography • Critical ethnography	• Gaining additional insights • Can you advanced techniques to present data	• Time-consuming • Safety and privacy concerns • Interviewer effect/influence
Phenomenological	Study of individual experiences and interpretations of the world	• Hermeneutic phenomenology • Empirical, transcendental, phenomenology	• In-depth understanding of individual phenomena; • Rich data from the experiences of individuals	• Difficulties in establishing reliability and validity • Researcher induced bias. • Small samples

4.3.1. Chosen Methodology

There are a number of GT theories (Charmaz, 2000; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990), the aim of the original GT theory is to discover theory from the data, however, theorists have identified their own methods to conduct GT and as such there a number of GT variances in methods which could have been applied. Strauss & Corbin, (1990) was the chosen methodology as it provided a structured and flexible approach in discovering the theory from the data.

Grounded Theory (GT) (Strauss & Corbin, 1990), was the chosen methodology and analytical procedure to explore the phenomena within this PhD. GT enabled the research process to develop a theoretical framework (to date this was lacking in the previous literature). According to Corbin and Strauss (1990), GT is an approach for looking systematically at qualitative data to generate a theory, which consists of coding and theoretical sampling. Employing GT helped produce a framework that could explain behaviour towards self-management in SA population by exploring patient's views and experiences (a bottom-up, rather than top-down holistic approach).

GT was developed by Glaser and Strauss (1967), it studies patterns and processes in human interactions (Cutcliffe, 2000). There has been an ongoing debate about the theory and methodology behind GT and the famous split between founders rising from personal and methodological differences (Bryant, 2009) which ended up with the publication of two competing books (Strauss & Corbin 1990; Glaser, 1992). The recent work of Kathy Charmaz (2000) who came up with the constructivist GT approach has also been influential. GT is a set systematic approach, which aims to recognise categories and concepts in the text (Corbin & Strauss, 2008). GT has been described as a method that "consist of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories 'grounded' in the data themselves" (Charmaz, 2006). The constant comparison method is a significant characteristic of GT as it entails the text to be compared and contrasted systematically. Data is collected continuously, and analysis is done immediately until saturation of the data has occurred, according to Strauss and Corbin, 1998, theoretical saturation is ‘the point in category development at which no new properties, dimensions, or relationships emerge during analysis’ (p. 143) this in return develops a theoretical model from the data.

Adopting the GT approach aims to understand the heterogenous culture within the SA population by providing an insight into the complexities that are associated with diabetes self-management and identifying a deeper meaning of their behaviours. GT uses social processes looking at multiple dimensions which provides a holistic understanding of the experiences faced with diabetes self-management in the SA population.

4.4. Recruitment

4.4.1. Study Setting

Due to the nature of the studies, a variety of participants were required to part-take in the research, e.g. health professionals, patients and family members. Interviews were carried out: For studies 1 & 4, typically in the health professionals place of work; and for studies 2 and 3, in the patients and family members homes (one interview was carried out in a coffee shop at the request of the participant, see chapter 7 study 2).

Health professionals were chosen for the first study, with the aim for the researcher to initially understand the care pathway system, and to get a feel for patient needs and difficulties as experiences from their health care providers. This study aimed to set the scene and provided insight on how to address the patients in the second study. The subsequent family member's study was added following the patients study given that their commentary often made referred to significant others influencing their diabetes care.

Study 1 (*Chapter 5*) was conducted with health professionals; recruitment initiation was conducted through emails, telephone conversations and snowball sampling. The second study (*Chapter 6*) recruited patients and access were gained through liaising with GP services and health centres; a protocol was set in place between the researcher and a point of contact to communicate. The third study (*Chapter 7*) recruited patients family members and friends sought access to participants directly recruited in the previous study, from the patients, who were asked to nominate a 'significant other'. In each of these GT studies, theoretical sampling was employed until reaching theoretical saturation (Strauss & Corbin, 1998) to ensure rigour in the analytical framework developed, from the exception of study 3 (*Chapter 7*) were data saturation was achieved.

Theoretical Sample

The ultimate goal of theoretical sampling is to develop and generate theoretical data. Glaser and Strauss (1967) defines theoretical sampling as "the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges" p.45. This sampling technique requires the researcher to collect data and analyse it at the same time, this guides the researcher into the next type of participant to recruit and what data needs to be collected. This procedure oversees the research process and does not allow the researcher to plan the data collection.

Given the inductive nature of theory generation, theoretical sampling, (including the point at which sampling ceased), was controlled throughout the study by the developed theory. Sampling discontinued once a point of saturation had been reached, whereby categories and their properties were considered sufficiently dense, and data collection no longer generated new leads (Glaser & Strauss 1967). Glaser (1992) has described this as the point at which the researcher has reached the full extent of the data, and thus “sampling is over when the study is over” (p.107).

4.5. Data collection

A range of data collection techniques are deemed suitable in qualitative research (*Table 4.3*). However, the most common techniques used are interviews, observations and focus groups (Legard, Keegan & Ward, 2003; Silverman, 2000).

Table 4.3: Overview of data collection methods

Data collection method	**Purpose**	**Benefits**	**Limitations**
Interview	Exploration of views, experiences, beliefs of participants about phenomena	• Opportunity to ask for feedback or clarification from participant straight away • Yield-rich data and new insights • Face-to-face contact with participants • Explore topics in depth • Can probe questions • The researcher has control and can be flexible in how the interview flows in different participants	• Can be expensive and time-consuming • The researcher may misinterpret information through recollection error, selective insights, participant wanting to please researcher. • Flexibility can consequently lead to inconsistencies through interviews • Interviews can produce a lot of information which can result in difficulty when transcribing
Focus group	Draw upon participants attitudes, beliefs, feelings experiences and reactions	• Easy to measure participants response as the researcher can also gather information such as facial expressions or body language. • Group interaction as the researcher can also interact with the participants, can ask follow-up questions and probe questions to gain a deeper insight. • Quicker to get information from focus groups than separate interviews.	• Can be time-consuming • Not as in-depth as an interview • Can be a small sample size which may not be a representative sample • Can be challenging to control group discussions as irrelevant topics may be discussed. • Participants can feel the pressure to give similar answers
Observation	Researcher becomes a participant in the setting that is being observed.	• Can gather direct information about the behaviour of individuals and groups • Researcher immerses into understanding the situation under study • Good opportunities to identify unforeseen outcomes • Natural and flexible setting	• Can be expensive and time-consuming • Can influence the behaviour of participants • As there are many people involved the observer may miss information leading to selective perception which may misrepresent data • The researcher does not have much control over the situation

4.5.1. Interviews

The purpose of conducting interviews was to explore the views, experiences and beliefs of individuals to offer a 'deeper' understanding compared to questionnaires (Silverman, 2000). Interviews are the most common form of data collection and provide a flexible way of exploring opinions and experiences. Prompts can be used to encourage responses, which can allow a deeper exploration of certain responses (Moser & Kalton, 1979; Warren & Karner, 2005). As interviews allow the participant to express their views, it may lead to exploring new phenomena's. There is room for flexibility when conducting interviews as you can make arrangements at a suitable time and location for the participants. There are three major types of interviews: structured (verbal questionnaires), semi-structured (conducted with little structure) and unstructured (conducted no structure) (Stuckey, 2013).

Semi-structured interviewers were deemed to be the most appropriate for this research as it ensured an adequate dialogue between the researcher and participants, yet allowed flexibility within the interview structure for the participants to lead and develop the conversation as appropriate to the topic (Adams, 2015).

4.6. Ethical considerations

Ethical approval was obtained from Liverpool John Moores University ethics committee: via proportionate review for study 1 (ref no. 114/NSP/028) (*Appendix 4.1*); For study 2 and 3 NHS ethics, IRAS, NHS governance, DBS clearance and Research and Development (R&D) approval was obtained from the Lancashire Care NHS Foundation Trust (ref no. 15/YH/209) and local NHS services (*Appendices 4.2 + 4.3*).

4.6.1. Overview of ethical considerations

4.6.1.1. Informed Consent

Before the research interviews began, the researcher (TP) verbally outlined the purpose of the study and requested the participant's consent to take part. Participants signed a consent form (in English or translated into Gujarati or Urdu) (*Appendices 5.3, 6.3 & 7.3*). With the patients, there was sometimes a delay before the interview could commence as some participants had a limited understanding of what research was. This delay allowed the researcher to build a rapport as they felt more comfortable in expressing themselves and felt they could relay the challenges faced by their management.

A participant information sheet (*Appendices 5.2, 6.1 & 7.2*) was also provided, outlining the purpose of the research, the procedures involved, and all foreseeable risks and discomforts to the subject. These included not only physical injury, but also possible psychological risks and benefits of the research to society and the individual human participant, and length of time the participant is expected to partake. Gaining informed consent allowed the researcher and participant to build a trusting relationship (Crow, Wiles, Heath, & Charles, 2006).

All signed consent forms, verbatim transcripts and audios of interviews were retained and kept in a locked filing cabinet where the researcher had sole access to these documents and recordings. All interviews were digitally recorded and transcribed verbatim (word for word), transcripts were stored on the password-protected laptop, and a University secured data storage drive and pseudonyms replaced real names.

4.6.1.2. Debrief

Once the interview was completed, the participants were given a chance to ask any questions in which the researcher would answer honestly and as thoroughly as possible. No concerns were raised in this research (*Appendices 5.5, 6.5 & 7.5*).

4.6.1.3. Protection of Participants

The researcher ensured the participants were not caused any distress and were protected from physical and mental harm. The researcher tried not to embarrass, frighten, offend or harm participants and remained empathetic with any negative emotions.

4.6.1.4. Deception

The participants were not deceived by the research; they were informed of the true nature of the study before the interview took place.

4.6.1.5. Withdrawal

Participants had the right to withdraw at any time during the interview process without reason, and such withdrawal did not affect their diabetes treatment.

4.6.1.6. Confidentiality & Anonymity

Confidentiality is regarded as the principle of privacy (Oliver, 2012). Participant's names and the data obtained was kept anonymous. Pseudonyms were given to the participants within the report.

The signed consent forms, audio recordings and transcribed interviews remain with the research team for five years and after that will be destroyed. The participants were made aware that the findings from the research were to be discussed with the research team, and anonymous quotes may be used as evidence in the PhD thesis or subsequent publications or conference presentations.

4.7. Data analysis

4.7.1. Adopted analysis - Grounded Theory

GT methodology and analysis (Strauss & Corbin, 1990) was applied throughout the study (*Table 4.4*). The GT process adopted simultaneous data collection and analysis, thus leading to theoretical saturation (Strauss & Corbin, 1998).

The data analysis for GT comprises three stages 1) exploring the codes, 2) concepts and 3) categories. This research adopted Strauss and Corbin’s (1990) approach, as follows:

1) ***Codes****:* To find underlying issues in the data, during the analysis of an interview the researcher will familiarise herself with words and phrases by identifying codes.

2) ***Open Coding:*** An Inductive process of breaking down, (examining, comparing and categorising the data) consisted of taking the inductive approach and involved the reading and re-reading of transcripts by the researcher who independently open-coded all transcripts. Discussions about the open codes identified a prominent theme regarding participants' concerns about cultural advice.
3) ***Axial Coding****:* (making connections between categories) this stage moves from inductive to deductive analysis as the data is assembled in new ways after open coding, by making connections between categories, from grouping together similarly themed open codes. Each code was given an appropriate label and memos that explored and expanded on the ideas, highlighting relevant quotes and related categories.
4) ***Selective Coding:*** (relating all the categories to develop a theory) this process involved selecting the core category and the central category around which the final analysis will be based and then relating it to all the categories to develop a theory.
5) ***Concepts:*** Codes are analysed, and similar themes are grouped.
6) ***Categories:*** Concepts are then grouped and regrouped to find categories, which lead to the development of a theory.

Table 4.4: GT process used for data analysis in this project

Component	Stage	Description
Openness	Throughout the study	Took great care to avoid applying or retaining any pre-conceived notions or theories amongst SA's. Theories were only derived following data analysis.
Analysing immediately	Analysis and data collection	Reflection with the DoS after each interview and discussed each interview.
Coding and comparing	Analysis ***Open Coding:*** The Inductive process of breaking down, examining, comparing and categorising the data. ***Axial Coding:*** This stage moved from inductive to deductive analysis as the data was assembled in new ways after open coding, by making connections between categories. ***Selective coding:*** Process of selecting the core category and the central category around which the final analysis was based and then relating it to all the categories to develop a theory.	Open coding required the application of a comparative method, (e.g. asking questions and making comparisons). Data was primarily broken down by asking simple questions, such as 'what', 'where', 'how' and 'when'. The data were then compared, and similar occurrences were grouped and given the same conceptual label. The process of grouping concepts that occurred most frequently is termed as categorising. Transcripts were read line-by-line. A code was allocated to each line to describe the text. The transcripts were re-read to make comparisons and similarities between the text. The open coding analysis leads to "refining and specifying any borrowed extant concepts" (Strauss & Corbin, 1998). Following the open code process, the transcripts were read once more to identify emerging themes from the codes found in the open-code process. A summary of each interview was written. This allowed the researcher to compare the transcripts with each other to find similarities and connections between the identified themes.
Memo writing	Analysis	Once each interview was conducted, the researcher wrote a case-based memo and discussed with supervisors. In these memos, the researcher reflected in what she had learnt from the interview, her experience, thoughts, feelings and any other useful information. The memos were used as

		prompts when analysing the data.
Theoretical sampling	Sampling and data collection	Be aware of identifying irregularities. Highlight and explain gaps, irregularities and conclusions.
Theoretical saturation	Sampling, data collection and analysis	Simultaneous between interviews and analysis.
Production of a substantive theory	Analysis and interpretation	Each study produced a GT framework (*Chapters 3, 5, 6, 7*).
Production of a Grounded Formal Theory (GFT)	Analysis and interpretation	Kearny, 1988, defines a GFT as a “suited to study of phenomena involving processes of contextualised understanding and action” p.180. The process of coding, constant comparison and theoretical sampling will be applied to the individual GF frameworks (*Chapters 3, 5, 6, 7*) to develop a GFT (Glaser, 1978; Kearny, 1997; Kearny, 2001; Strauss, 1987) (*See chapters 8 & 9 for more detail*).

4.8. Researcher reflexivity; reliability and validity

To assess the reliability and validity of qualitative research is difficult. However, qualitative researchers such as Lincoln & Guba (1985) have described ways to achieve trustworthiness by adopting four methods: credibility, transferability, dependability, and conformability (*Table 4.5*). To ensure research quality, validity and reliability of the analysis, the following components were considered throughout.

Table 4.5: Overview of reliability and validity

Credibility	The interviews were audio recorded and were transcribed verbatim.
Confirmability	A detailed analysis of records was kept to write this piece of research. Analysis of each transcript was done as soon as possible, and case-based memos were written after each interview. To generate a theory, constant comparative methods were used, and the later interviews aided theoretical sampling.
Triangulation	Occurred between researcher and research team by discussing interviews and creation of axial codes throughout the interviews and the simultaneous analysis process.
Reflexivity	The researcher wrote notes and reflection memos following each interview and discussed these reflections during supervision to evaluate her interviewing technique and to maintain reflexivity (McGhee, Marland & Atkinson, 2007). The researcher was SA ethnicity, therefore recognising the role of researcher bias, the researcher had regular meetings with supervisors (two female Caucasian, one male Nigerian). As a multi-ethnic research team, we were able to offer a balanced analysis. This reflective approach to analysis helped to create a rich and deep discussion of the findings across the data set.

The researcher could speak English, Urdu, and Gujarati fluently; participants were interviewed in their preferred language of choice. To ensure the language (spoken) of participants did not act as a barrier to recruitment and engagement, a mixture of English and Gujarati interviews were carried out and were translated and transcribed into English. More detail of the process will be described in the respective studies chapter.

It was anticipated that due to the nature of the sample, some of the target population would not be able to speak English. To ensure inclusion of a more comprehensive participant pool interviews were also conducted in, Gujarati and Urdu as the researcher could speak those languages. The translation was considered in the research process, where the all the necessary forms were translated into Gujarati and Urdu to ensure that participants were fully aware and had an understanding of what the research was carrying out so that they could express themselves accordingly. The researcher translated all the non-English interviews to ensure that the core meaning of what participants were conveying was not lost, this was ensured by transcribing interviews immediately and writing memos regularly. Brislin (1970, 1980) suggested, two competent bilingual translators who are familiar with the research area and can translate back the original language can be a method to ensure that the translation was accurate. This was completed by Ishfaq Vaja, a fellow PhD researcher carrying out research in Diabetes prevention in SA population. Ishfaq could speak Gujarati and Urdu. Therefore, it was agreed that an interpretation accuracy would be checked on a random sample (n=9) of interviews. The transcripts had already had a pseudonym or other identifiable material removed, and the audio recordings were edited with blank recording if personally identifiable information had been mentioned during the recording itself. This process ensured anonymity of the participant remained, and Ishfaq was not privy to participant identifiable information.

To ensure reliability and validity was implemented throughout the research, the specified GT processes were followed across all the studies, ensuring the credibility of the research. Triangulation occurred via the research team. Quality was ensured throughout the research, through continuous reflexivity of activities, thoughts and feelings. The researcher's previous academic experience included the completion of a BSc Psychology (2011) and MSc Health Psychology (2012). Completing a BSc and MSc allowed her to gain some initial research experience, where qualitative research was employed for both theses. However, it was acknowledged that the intensity and depth of qualitative research conducted throughout this PhD has advanced over time, and the researcher's knowledge, skills and expertise have improved since commencing the PhD process.

Peer support is recommended within qualitative studies because it has a positive effect on reducing the researcher's bias (Oktay, 2012). Peer support was provided by the DoS, who has expertise in diabetes and qualitative research. This supervision challenged the researcher to reflect, during both data collection and analytical processes, on how to acknowledge and mitigate any potential bias held. For example, the researcher was from an SA background, without a diagnosis of T2D but with own family members who had T2D, she consulted with the DoS on a regular basis throughout, and in addition, the researcher maintained a reflective journal to evaluate her experiences and expectations (Berger, 2015). By the time study, 2 (chapter 6) with the patients was conducted, the researcher was more confident in her interview skills and was able to connect with patients. Although recruitment was through health organisations, i.e. GPs and health centres to provide details of the participants, this was difficult at times to get a reply and this created frustration.

Building a rapport with the patients by the time study 3 (chapter 7) commenced with family members and friends, the researcher felt much more confident with her interviewing skills. The difficulties faced were that ethical approval was not granted to conduct the third study until the second study was near completion. Due to the nature of the sample, some participants did not want to provide details of their family member or friend, so this restriction limited the sample size of study 3 (chapter 7).

Alongside the PhD, the researcher has been simultaneously completing the British Psychological Society Stage 2 Qualification in Health Psychology to become a Chartered Health Psychologist. The Stage 2 training has encouraged to engage in applied health care settings. These opportunities have helped to enhance understanding of healthcare delivery (e.g. within diabetes services) adding value to the interpretation of data across this qualitative PhD research.

As a SA female, I (the researcher) was genuinely passionate about improving the health and wellbeing of SA patients and had a specific interest in Diabetes. My researcher motivation stemmed from a family history of T2D, which included grandparents and mother. Coming from a SA background and living in a tight community, the researcher was able to recognise the high prevalence of T2D in the SA population and wanted to seek a deeper understanding and find ways to overcome the challenges and barriers that are faced by this population.

It was acknowledged from the outset that the researcher's background might create bias within the research process. However, precautions were taken to ensure that any bias was mitigated throughout. The research team helped manage any bias and conduct quality assurance. Having a multi-ethnic supervisory team helped to maintain a rounded perception of the research and created meaningful discussions about the interpretation of data. Throughout this PhD, regular, ongoing meetings with DoS and with the other supervisors. On-going reflection has been continuous, and thorough processes have been employed throughout the PhD (Gibbs, 1988) (*Appendix 4.4*)

The following three chapters present each individual qualitative study, and specific methodology detail are provided within.

Chapter 5: Study 1- A qualitative study investigating health professionals’ perceptions and experiences of supporting T2D self-management in SA patients

Study 1 - Chapter overview

British SA people experience an increased risk of developing T2D, and health professionals play an important role in facilitating diabetes self-management. Although numerous qualitative studies have explored health professionals’ views regarding diabetes care generally, there is a paucity of research exploring their views on diabetes management in SA patients specifically.

This study aimed to explore health professional’s views regarding adherence to diabetes self-management guidelines amongst SA patients with T2D.

Fourteen semi-structured interviews were conducted with health professionals who supported patients with T2D in the North West of England (Bolton, Preston, and Blackburn). Grounded theory methodology and analysis (Strauss & Corbin, 1990) was employed. Simultaneous data collection and analysis informed recruitment of participant,s as part of the process of theoretical saturation.

The analysis incorporated themes referring to inadequate culture-specific knowledge, and misconceptions regarding SA culture, in general, and diabetes care in particular. Health professional’s lack of culture-specific education and their ethnicity seemed to affect their perceptions and interactions with patients.

These findings suggest a need to consider the implications of ethnicity as a key concept for health professionals to provide personalised patient care, this may be transferable to other health conditions, and not just apply to patients accessing diabetes care.

5.1. Introduction

The doctor-patient relationship can have a profound impact on diabetes management (Brez, Rowan, Malcolm, Izzi, Maranger, Liddy et al., 2009; Clark & Gong, 2000; Holman & Lorig, 2000). When patients are initially diagnosed, they rely on health professionals to give them information and advice about diabetes (NICE, 2015). Health professionals understand the evolution of the disease, the effects of treatment, and interact with patients on a one-to-one basis (Nunstedt, Rudolfsson, Alsén, & Pennbrant, 2017).

Clinical guidelines (NICE, 2015; p. 7) state that patients should be provided with evidence-based information personalised to their needs. Such information should be culturally appropriate and accessible to people with additional needs (Burke, Sherr, & Lipman, 2014; Graffigna, Barello, Bonanomi & Menichetti, 2016; Kennedy, Rogers, & Peter, 2007). To achieve good clinical outcomes, it is vital for health professionals to understand the cultural needs of their patients, particularly regarding engaging with clinical advice (Fleming & Gillibrand, 2009; Osman & Curzio, 2012).

5.1.1. Literature review

Numerous studies have examined health professional’s attitudes and interactions with patients about healthcare (Babelgaith, Alfadly, & Bahari, 2013; Lang, Floyd, Beine, 2000; Odili & Oparah, 2012; Snoek, 2000). Good doctor-patient interactions have been associated with positive health outcomes such as engaging in self-management behaviours, improvement in general health and fulfilment of patient expectations (Ha & Longnecker, 2010; King & Hoppe, 2013).

5.1.1.1. Health professional knowledge, training and experiences in offering diabetes care

One factor that plays a role in patient outcome is the attitude of health professionals towards diabetes management (Larme & Pugh, 1998; Sharp & Lipsky, 2002; Weinberger, Cohen & Mazzuca, 1984). Clark and Hampson (2003) investigated UK health professionals' diabetes-related experiences and attitudes. Health professionals completed the Diabetes Attitude Scale (DAS-3) which assessed: 1) prior training in diabetes care; 2) treatment of diabetes compared with the treatment of five other long-term chronic conditions; 3) beliefs about the effectiveness of treatment of hyperglycaemia in preventing diabetes complications; and 4) confidence in their therapeutic actions, evaluation of their work-load and resources to effectively treat their patients with diabetes. The professionals considered diabetes harder to treat than other chronic conditions, such as asthma. They also reported inadequate time and lack of resources, suggesting that these experiences negatively affected patient outcomes.

Jeavons, Hungin, and Cornford (2006) explored doctors' and nurses' attitudes and beliefs towards treating patients with T2D. They conducted focus groups with twenty-three UK health professionals working in primary care. It was concluded that patient outcomes would be enhanced by receiving input and support from GPs with specific interests in diabetes and for more specialist nurses in diabetes to give advice.

Research has further explored attitudes and identified that additional health professional training could improve patient outcomes. Bani-issa and colleagues (2015) considered the attitudes of 337 Brazilian's health professionals towards diabetes. Findings highlighted the variance in perceptions and attitudes towards diabetes management across different professional groups. Doctors scored significantly higher on positive attitudes, the need for advanced training, the seriousness of diabetes, the value of tight glycemic control, and psychosocial aspects of diabetes more than other professional groups. Nurses had the highest positive attitude toward patient autonomy followed by dietitians, pharmacists and physicians. The results suggest that additional training led to positive attitudes.

Torress, Rozemberg, Amaral, and Bodstein (2010) explored perceptions, knowledge, and practices of twenty-three primary-care health professionals. These health professionals provided patient education to people with T2D and took part in focus groups to discuss their patient education practices and to explore their challenges in providing effective patient education in Brazil. Four key issues emerged 1) lack of training and knowledge among the health professionals on some aspects of diabetes; 2) perceptions of work conditions and organisation; 3) issues related or attributed to the patients themselves, and 4) diabetes care model. The health professionals suggested that training on diabetes knowledge could significantly improve their skills to better support the management of diabetes in their patients.

A study conducted by George, Warriner, Anthony, Rozario, Xavier, Jude et al. (2008) explored UK postgraduate trainee doctor's confidence, practices and perceived training needs in diabetes care. Only 13% (n=11) recalled specific training in diabetes, and of the total sample, only 28% felt sufficiently confident in providing advice. Moreover, a lack of confidence has been shown to influence the quality of diabetes negatively (George, Warriner, McGrane, Rozario, Price, & Wilmot et al., 2011).

A study conducted by Herring, Pengilley, Hopkins, Tuthill, Patel, Nelson, et al. (2013) designed a diabetes education tool: *'Piecing Together Diabetes',* for UK hospital-based health professionals. The evaluation suggested that the health professionals had significantly improved confidence and knowledge. The tool may have also enabled the health professionals to improve the quality of diabetes care they offered. For example, there was a significant improvement in patients' blood glucose monitoring; and hypoglycemic outcomes.

The factors highlighted above, e.g. attitudes and confidence, influence the delivery of care. When health professionals receive limited training or have low confidence, this leads to the reduced acknowledgement of patient needs, and as a result, health professionals adopt more prescriptive methods to promote self-management and build patient-professional rapport. A study conducted in Belgium (Wens, Vermeire, Van Royen, Sabbe, & Denekens, 2005) conducted a focus group study to examine forty General Practitioners (GPs) expectations of their patients' adherence to diabetes self-management recommendations. The GPs' reported problems with the patient's lack of knowledge. However, frequent communication tailored care and working within a multidisciplinary team resulted in better patient outcomes. GPs' felt that their efforts did not always meet the patients' expectations and therefore, GPs' adopted an authoritarian attitude and used prescriptive methods such as shocking the patients, pressuring them and threatening hospital referral (Blakeman, Macdonald, Bower, Gately, & Chew-Graham, 2006). However, such tactics have been suggested to be less effective at ensuring sustainable behaviour change (Rollnick, Butler, McCambridge, Kinnersley, Elwyn, & Resnicow, 2005).

Moreover, Bostrom, Isaksson, Lundman, Graneheim, and Hornsten (2014) conducted an observational study in Sweden to explore the interaction between Diabetes Specialist Nurses (DSNs) and patients with T2D during group sessions about self-management. Content analysis revealed several themes: 1) becoming empowered; 2) approaching each other from different perspectives, and 3) struggling for the control of authority. A patient centred approach was identified as most important. The DSN’s needed to be aware of the patient’s individual needs and avoid responding to patients in a normative way. Positive interactions strengthened patient’s self-management and had a positive effect on the DSNs performance.

The literature highlighted factors that influence health professional’s delivery of care in the UK and internationally. In summary, health professionals’ attitudes, knowledge and confidence influence their delivery style. Given the previous literature on diabetes care in ethnic minority groups (Khunti et al., 2009; Patel et al., 2014) and the increased diabetes risk amongst SA’s (Diabetes UK, 2014; DoH, 2007), self-management issues in the SA population are still prevalent (Pardhan & Mahomed, 2004; Stone et al, 2010) and further research is required to investigate this issue further.

5.1.1.2. Culture and SA population

Cortis (2004) interviewed thirty UK nurses caring for hospitalised diabetes patients in West Yorkshire. The population of Yorkshire is ethnically diverse, “people born in Pakistan represent the most numerous (19%) non-UK born group in Yorkshire & Humber” (Censcus, 2011, p. 2). Bradford is a city within West Yorkshire and has the largest proportion of people of Pakistani ethnic origin (20.3%) in England. Despite the ethnic diversity of the population in West Yorkshire, the nurses reported that they had a limited understanding of the Pakistani culture, which made it challenging for them to empathise with their patient needs.

Similarly, Fagerli, Lien, Botten, and Wandel (2005) interviewed 12 health workers in Norway on their experiences of working with patients of Pakistani descent. The health workers identified many challenges such as language barriers, lack of knowledge about the condition and time constraints with the patients. Empathy and equality were recognised to be essential characteristics of providing care. However, it was recognised that health professionals had limited multicultural knowledge, which limited the opportunities to empathise and offer equality by reducing their offer of a personalised patient care approach. The health workers reported that patients did not want to take control and expected to receive prescriptive advice of being told what to do.

A UK study conducted by Hawthorne and colleagues (2003) explored the perspectives of various Primary Health Care Teams (PHCT) who worked with Bangladeshi patients in Cardiff. Hawthorne et al. (2003) reported that communication, explicitly understanding language differences, resulted in barriers to optimal care and staff became frustrated with patients not using the health service appropriately, for example, not attending appointments. It was also suggested that due to cultural diversity, it would be beneficial to develop racial awareness training for clinical staff.

Capell (2008) carried out a study to assess the relationships between cultural competence and ethnocentrism. Seventy-one health professionals completed two validated assessment tools: The Inventory to Assess the Process of Cultural Competence Among Healthcare Professionals–Revised (Campinha-Bacote, 2003), and the Generalized Ethnocentrism Scale (Neuliep, 2002). Based on the findings, the study concluded that if health professionals were mindful of the cultural differences, this could improve care outcomes.

Previous evidence suggests health professionals’ lack of knowledge regarding patients ethnic and cultural needs which affect the quality of care, and therefore negatively influences patients' self-management behaviours. However, while certain interventions (Herring et al., 2013) have shown some improvements in knowledge, and thus patient outcomes, the issues around poor diabetes self-management continue.

5.1.2. Summary & Rationale

Overall, the studies reviewed were not all UK-based, but are nevertheless relevant to the discourse, it is clear from existing research that health professionals’ attitudes, knowledge, and confidence are implicated in the quality of care received by patients with T2D. This was established in studies in the UK (Clarke & Hampson, 2003; Jeavons et al., 2006; George et al., 2008; George et al., 2011; Herring et al., 2013), Europe (Bostram et al, 2012; Wens et al, 2005) and worldwide (Anne & Larme, 1998; Bani-issa et al., 2015; Capell, 2008; Sharp & Lipsky, 2002; Torress et al., 2010; Weinberger et al., 1984). However, many studies have explored the impact of culture on diabetes care (Jepson et al., 2012; Lawton et al., 2006; 2008). The issue here is that few studies have explored health professionals' attitudes toward diabetes care in SA populations specifically. Thus, there is a limited understanding of their views in this context and the impact on patient care. (Capell, 2008; Cortis, 2004; Fagerli et al., 2005; Hawthorne et al., 2003). There is a need to better understand health professionals' knowledge and experiences of care for SA patients with diabetes.

5.1.3. Aims

This study aimed to explore health professionals' perceptions and experiences of providing diabetes care to SA patients, using GT methodology (Strauss & Corbin, 1990).

5.2. Method

5.2.1. Design

Semi-structured interviews and GT analysis (Strauss & Corbin, 1990) was employed (*Figure 5.1*) to generate a theoretical framework that explored health professionals' perceptions and experiences providing diabetes care for SA patients (See chapter 4 for detailed information on grounded theory process and analysis).

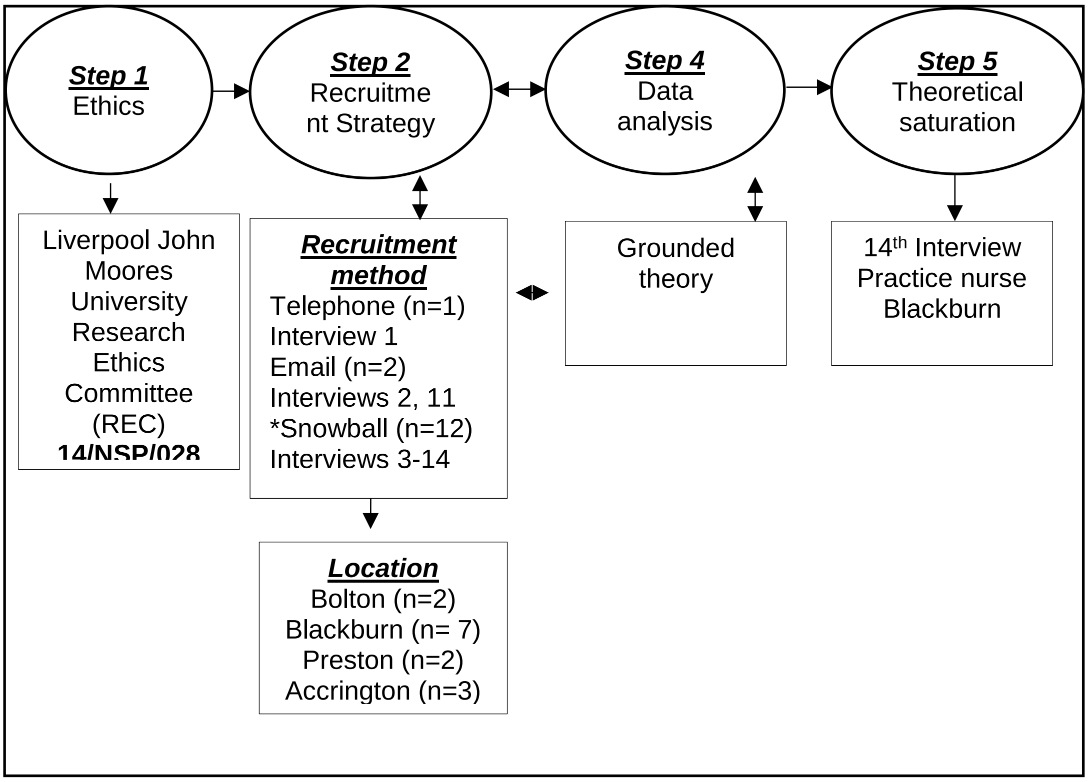

Figure 5.1: Overview of study methodology

*Snowball sampling strategy (Vogt, 1999). Participants were asked to recommend eligible participants, for example, interview 1 recommended the study to interview 3.

5.2.2. Initial Purposive Sampling

Participants were eligible for recruitment if they were an NHS health professional, supporting patients diagnosed with T2D diabetes. Health professionals (e.g. GP's, Practice Nurses, and DSN) from a variety of primary and secondary healthcare settings around the North West of England (Bolton, Blackburn and Preston) were contacted. Initial recruitment was through opportunity sampling (*Figure 5.1 step 2*), i.e. health professionals were invited to participate in the study via telephone and email correspondence).

The initial interview was transcribed verbatim, and analytical discussions between the research team helped determine the characteristics of whom to recruit next *(Table 5.1).* In addition to opportunity sampling, snowball sampling was utilised to achieve theoretical sampling (Morse, 2008). Simultaneous data collection and analysis occurred throughout the study seeking to reach theoretical saturation (Strauss & Corbin, 1998) as an endpoint.

Table 5.1: Evolution of theoretical sampling and interview questions

The first interview was conducted with a Diabetes Specialist Nurse who was contacted by telephone. This interview gave an insight into the diabetes setting, approaches, and who was involved. From this interview, it was recognised SA health professionals play a key role in SA specifically diabetes care, so it would be beneficial to interview one of her colleagues who works with the ethnic minority population. This interview identified the need to interview primary care staff such as GPs and nurses as they play an important role and SA health professionals.
The second interview was with a Diabetes education coordinator/ Dietician; this participant was recruited through email. This interview focused mainly on management of diet, but she also pointed out other issues of self-management like language barriers and how they use link-workers as they play a role in the diabetes management and will have a deeper insight into issues the SA population face. This interview identified the need to interview SA health professionals, as they seem to influence the delivery of care.
The third interview was with an SA diabetes specialist nurse who was a colleague of the first participant. This interview helped highlight the need for culturally specific knowledge, and the role of specialist diabetes nurses. This participant was able to transfer her own cultural experiences and empathise with patients.
The next three interviews were conducted at a diabetes service where they dealt with a high ethnic minority group. These participants contacted the researcher directly (snowball sampling, Vogt, 1999). The PIS which had the researcher's contact details. The first interview was with a Caucasian Diabetes Specialist Nurse. However, it became apparent that there was lack of awareness of the different types of SA populations, I.e. different religions and ethnicities that are all classified under the SA umbrella, and this participant admitted that having an SA colleague helped delivery of care. The next interview was with a Dietician (Service manager) who was from an SA background. In this interview, it was found that the SA health professionals bring their own experiences and apply to their workplace. The third interview was with another Diabetes Specialist Nurse (Team Leader) who was Caucasian, from this interview the participant suggested that all patients struggle, and it is all about the individual as opposed to culture.
The Diabetes Link-worker interview was interesting as I was able to see the difference between the clinical experience of the health professionals and the social experience of the link-worker; both sets of skills are valuable as they both play an important role.
Most of the previous interviews were carried out in secondary care, and it was identified that lack of self-management could lead to long-term complications, so two extended scope podiatrists from secondary care were interviewed to see if self-management improves when the complication occurs. In these interviews, it was found that primary care plays an important role in diabetes management.
Most of the interviews mentioned the role of primary care specifically the role of the GP as they are the health professional who usually first diagnoses the patient. An SA GP was interviewed, and in this interview, it was evident that time spent with a patient is an issue as it was found that there was not enough time for a GP to build a rapport with the patient. I was advised that interviewing a practice nurse would be beneficial as they deal with the management.
A consultant physician was then interviewed; this SA health professional had years of experience, and it was suggested that the concept of diabetes is not properly understood in the SA patient so there is a lack of understanding which influences management.
A primary care Caucasian practice nurse was interviewed, in this interview the difference between a diabetes specialist nurse, practice nurse was apparent as the knowledge, and experience of diabetes differed. At this interview, it was not very detailed, and the practice nurse did not give much in-depth insight, she was reluctant to provide information perhaps for fear of being criticised. It was decided interviewing another practise nurse would be useful.
Another GP was recruited through email, in this interview, the SA GP was very passionate about diabetes, he was aware of the influences of culture, but the lack of resources available in primary care such as access to dieticians whom he felt are important did influence care.

The last interview was a practice nurse; this practice nurse was more aware and gave more insight into diabetes management and SA culture. Once open coded was completed from the interview, it was found that the re-occurring themes were emerging from the data.
Theoretical sampling was achieved by recruiting participants who were directly involved in the care of diabetic patients.

Given the inductive nature of theory generation, theoretical sampling, (including the point at which sampling ceased), was controlled throughout the study by the developing framework (*Table 5.1*). Sampling discontinued once the research team deemed a point of theoretical saturation had been reached, whereby categories and their properties were considered sufficiently dense, and data collection no longer generated new interpretations (Strauss & Corbin, 1998). Glaser (1992) has described this as the point at which the researcher has reached the full extent of the data, and thus “sampling is over when the study is over” (p.107).

<u>Overview of participants</u>

Semi-structured interviews were conducted with fourteen health professionals. Ten females and four males with a mean age of 51.25 years (range 32- 58 yrs.). Eight of the participants were White British, while six were SA (sub-groups; n=3/Indian, n=1/Pakistani, n=2/unknown) (*Table 5.2 for characteristics of participants*). Seven worked in a hospital setting; four were from Primary Care General Practice and three from Community Health Services. On average the health professionals had been employed in their current for roles for 18.42 years (range 3-40).

Table 5.2: Characteristics of participants

	Name (pseudonym)	Age	Gender	Ethnicity	Job Title	Years in Job	Service Employed	Area
1	Bella	44	Female	British White	Diabetes Specialist Nurse	13	Hospital Clinic	Bolton
2	Ariana	48	Female	British White	Diabetes Specialist Dietician / Diabetes Education Coordinator	26	Community Health Service	Preston
3	Jasmin	48	Female	South Asian	Diabetes Specialist Nurse	24	Hospital Clinic	Bolton
4	Leila	58	Female	British White	Diabetes Specialist Nurse	40+	Community Setting	Accrington
5	Issac	48	Male	Indian	Dietician (Service manager)	3	Hospital Clinic	Accrington
6	Mia	44	Female	British White	Diabetes Specialist Nurse (Team Leader)	9	Hospital Clinic	Blackburn
7	Elsa	47	Female	Asian, Gujarati	Diabetes Link-worker	15	Lancashire Care Foundation Trust	Preston
8	Amelia	50	Female	British White	Extended Scope Podiatrist	28	Hospital Clinic	Blackburn
9	Jenson	54	Male	British White	Extended Scope Podiatrist	31	Hospital Clinic	Blackburn
10	Aiden	32	Male	British Pakistani	GP	10	GP/ Hospital Clinic	Blackburn
11	Olivia		Female	South Asian	Consultant Physician	15	Hospital Clinic	Blackburn
12	Ava	48	Female	British White	Practice Nurse	10	GP Practice	Blackburn
13	Logan		Male	Indian British	GP	20	GP Practice	Accrington
14	Daisy	46	Female	British White	Practice Nurse	14	GP Practice	Blackburn

5.2.3. Materials

A semi-structured interview schedule (*Appendix 5.1*) was determined by the topics and issues identified from the analysis taken from the meta-synthesis (*Chapter 3*). The key topics for the interview schedule were divided into two sections, the first section focussed on general diabetes care, and the second section explored knowledge of SA culture (*Table 5.3*). Interviews included open-ended questions to allow participants the opportunity to explain their experiences fully.

Table 5.3: Interview Schedule

Key Topics
For patients with type 2 diabetes what are the key issues regarding self-management that they have to consider?
What advice do you offer them?
Do you think there are differences within South Asian populations (e.g. Bangladeshi compared to Pakistani)?
What are the key issues South Asian population faces in self-management?
What barriers does this population face?
What training do you have to complete that is relevant to this population/ diabetes?
How confident are you supporting clients who are South Asian with diabetes?
Do you provide information differently to South Asians compared to Caucasian?

5.2.4. Procedure

The health professionals were provided with a participant information sheet, (PIS, *Appendix 5.2*) which informed participants about the purpose of the study and the risks and benefits of taking part. Those willing to participate were asked to sign a consent form (*Appendix 5.3*) and agree a convenient interview time and location. The participant filled out a demographic form (*Appendix 5.4*), which collected data on age, gender, job title, years in the job and which service they were employed. All interviews took place in the participants' place of work, in a private room, taking a mean duration of 28 minutes. Once completed, the researcher switched off the recorder, thanked the participant for taking part, and asked if they had any questions and debriefed (*Appendix 5.5*).

5.2.5. Reliability and Validity

Reliability and validity were ensured as interviews were audio recorded and were transcribed verbatim, constant comparative methods were used to aid theory generation. Triangulation was adopted as the research team met regularly throughout the interviews and the simultaneous analysis. As this was one of the first studies as part of the PhD, the researcher wrote notes and reflections, and discussed these with the DoS to evaluate the employed interviewing technique.

5.3. Analytical procedure

GT methodology and analysis (Strauss & Corbin, 1990) was applied throughout the study. The GT process adopted simultaneous data collection and analysis, thus leading to theoretical saturation at interview 14 (*Figure 5.1*) (Strauss & Corbin, 1998). A total of 1821 codes were identified through the open coding process (*Appendix 5.6*). Subsequently, thirteen axial codes were reviewed (*Appendix 5.7*) with various supporting memos (*Appendix 5.8*). Selective coding commenced and reorganised into a framework (*Figure 5.2*). Three core categories and three subcategories formed the basis of the final theoretical framework. The analysis referred to verbatim extracts of data as evidence to support analytical commentary and quotes were coded with the following information: Interview number (Int: 1-14), Gender (Male, M; Female, F), Ethnicity (Caucasian, (C); South Asian, (SA); Line number (s), Job title). *E.g. (Int 11, F, (C), 100-110, job title).*

5.4. Analysis

Three core categories (1) *Health professional's reflections on SA patients*; (2) *Delivery of diabetes care,* and (3) *Patient understanding and engagement with diabetes care)*. Three subcategories (1) *Knowledge of cultural, ethnic and religious diversity: SA sub-group recognition and SA experience,* (2) *Health professionals experience supporting SA patients – Patient-provider experience,* and (3) *SA knowledge of diabetes and influence towards engagement* were presented in a GT framework (*Figure 5.2*).

5.4.1. GT framework:

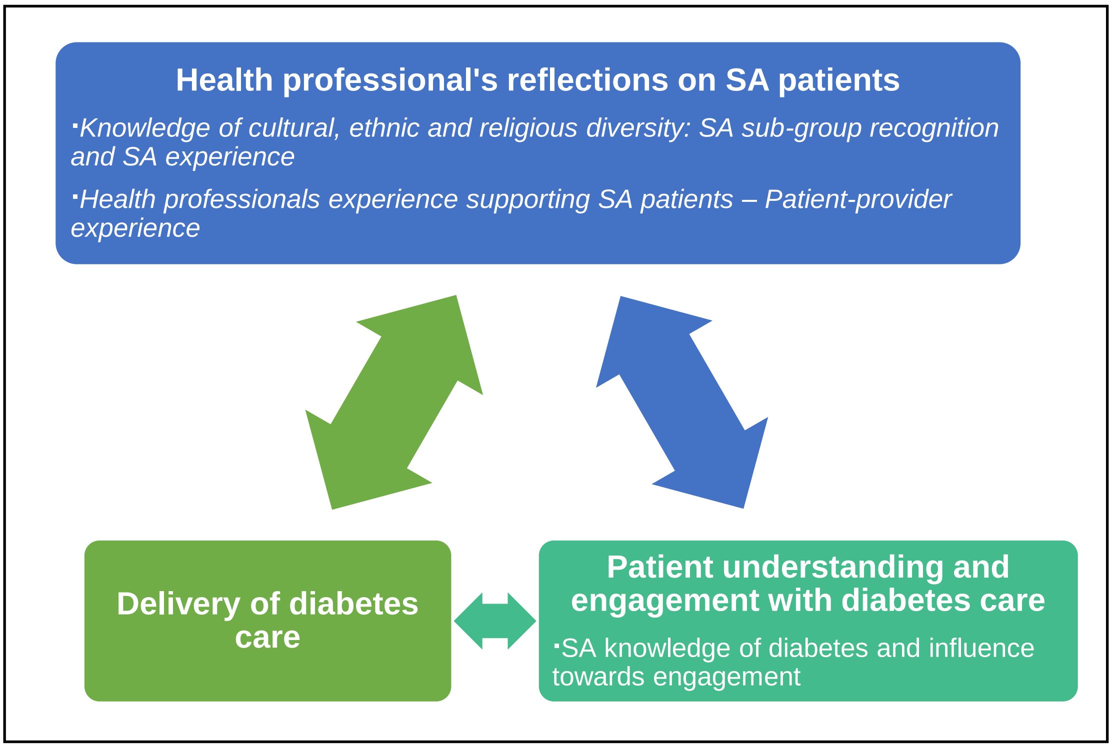

Figure 5.2: Cultural conflict in the delivery of health service

Core category: Health professional’s reflections on SA patients

The health professional's ethnicity and culture appeared to influence the delivery of the diabetes care they provided. Health professionals who were SA were more likely to report adapting advice to meet the cultural needs of the SA patients. Although some Caucasian health professionals reported that over time they became more familiar with SA cultural and religious needs (e.g. awareness of religious obligation such as Ramadan), most acknowledged that they did not routinely tailor diabetes advice in response to a patient’s ethnicity, culture, or religious beliefs, although they compared their work practices with SA colleagues.

Sub-category: Knowledge of cultural, ethnic and religious diversity: SA sub-group recognition and SA Experience

This sub-category highlighted health professional’s recognition of SA (sub) groups and reflected on their experiences that improved their knowledge. Most of the health professionals recognised that both ethnicity and religion could influence a patient’s engagement with diabetes self-management behaviours. Some felt that diabetes was a difficult condition to manage for all patients, regardless of ethnicity, religion or cultural beliefs, and as such this was not considered a priority topic.

> *There's no, I mean, it depends on education, and how educated people are, but that goes across the board. So no, I think that there's no real major differences with the self-management, to be honest.* (Int6, F, (C), Diabetes Specialist Nurse (Team Leader), Lines, 97-99)

Although some health professionals believed, ethnicity did not influence diabetes care, when probed, ethnic differences were apparent.

> *Within the community have a lot of knowledge about diabetes, but their knowledge is often a bit...is…can be quite different to the white community in respect of complications.* (Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, Lines, 322-325)

AND

> *Yes. I mean, I would say the Asian population has a very low understanding of their diabetes, don't prioritise it, a lot are in denial. Maybe that's because they don't quite understand the consequence of the disease.* (Int5, M, (SA), Dietician (Service manager), Lines, 110-112)

Health professionals recognised patients' expectations and experiences of care differed according to their ethnicity.

> *In our Caucasian sessions, our standard session for education, for example, we start them at 20 past 9, and we know that just doesn't work. (Laughter) For our South Asian sessions, you know, we basically think right, we'll start at half nine but we will...we'll say half nine but we wouldn't start until 10, and they'll be a period when people turn up (Laughter).* (Int2, F, (C), Diabetes

> Specialist Dietician/ Diabetes Education Coordinator, Lines, 490-495)

AND

> *‘They (SA patients) tolerate ill-health. If they're not feeling well, "Oh well, I'll just go to sleep and have a lie-down. Oh, you know, next week I'll feel better". I probably think that other maybe Caucasian people are less tolerant. "I'm not well for two days", they're off to the doctor, something's wrong. So they get seen earlier, they get treated earlier, things get changed earlier. The South Asian people, it's crisis intervention. They only ever come when there's a serious problem’.* (Int3, F, (SA), Diabetes Specialist Nurse, Lines, 224-229)

The health professionals suggested that SA patients had more difficulty with T2D management compared to their Caucasian counterparts. However, when probed on the various sub-groups within the SA population, the majority of Caucasian health professionals were not able to distinguish between different SA sub-groups and recognise differences in patient needs. For example, describing the diverse SA sub-group populations.

> *Indian versus Bangladeshi I couldn’t tell you any particular information about that, but we really class all…everybody as South... Because really most of the population that seem to have settled in Bolton are South Asian, but I couldn’t tell you much about Indian versus*

> *Bangladeshi.* (Int1, F, (C), Diabetes Specialist Nurse, Lines, 309-315)

SA health professionals were able to explain the ethnic, religious and cultural variations that exist within the SA populations (e.g. Indian/Pakistani; Muslim/ Hindu). These health professionals referred to their personal experiences and own ethnic backgrounds, which subsequently gave them greater insight and knowledge of the individual differences across SA patients.

> *There's cultural taboos. I will check a patient's life or psychs, just because the nurses might not have time. I won't do that with an Asian woman because usually, they don't really want that. Usually, a Caucasian woman, if she's sat where you are, and I'm sat in the vicinity, will be quite happy to show us her lipos. With an Asian woman, I would probably leave the room or go to the other side of the curtain. So it does mean that certain parts are restricted because certain things can't be done by certain healthcare professionals*. (Int5, M, (SA), Dietician (Service manager), Lines, 180-185)

It is noteworthy that SA health professionals, while more knowledgeable about the SA subgroup populations, were more likely to report specific stereotypes of the SA sub-groups. For example, previous literature suggests that many patients with diabetes struggle with self-management behaviour, regardless of education level (Zeh, Sandhu, Cannaby, & Strut, 2012). However, it was perceived that Indian patients were better educated and thus engaged more effectively with self-management behaviours, than their comparison SA subgroups (e.g. Pakistani and Bangladeshi patients).

> *Yes. The Indians tend to adapt more, and I think because of the fact that they're pushing - they have more of an appetite for education and obscuring themselves, generally.* (Int10, M, (SA), GP, Lines, 170-173)

AND

> *Most of the Indian population in the country is much more educated compared to Bangladeshi population or Pakistani population. Again you find most Indian population more towards the, what's the word? professional side.* (Int13, M, (SA), GP, Lines, 167-169)

Moreover, patients from Pakistani and Bangladeshi sub-populations were reported to be the hardest to reach patient groups. This may indicate that there are distinct individual differences in engagement and communication practices for these SA sub-groups that have not yet been explored.

> *Yes, and it's quite sad really because the biggest proportion of people that are not utilising it is the Pakistani community. And you know we have one of the girls at the hospital who's the link worker and everything,*

> *and over the years, you know, we've done lots of different things to try and engage this community group. And I would probably say they're the hardest to engage….* (Int3, F, (SA), Diabetes Specialist Nurse, Lines, 175-178)

Subcategory: Health professionals experience supporting SA patients – Patient-provider experience

The health professionals were able to reflect on their experiences of supporting patients from ethnic minority backgrounds.

> *No, not at all, no. My previous practice I worked at was very high Asian. This was in Accrington, and it was very high Asian population, so I think I was thrown in at the deep end there. I learnt a lot from that respect, but nothing, no specific training. I think it's just all experience really.* (Int14, F, (C), Practice Nurse, Lines, 208-211)

Those who had more experience, in terms of location (working in areas of high SA populations) and length of service as a health professional supporting patients with diabetes, reported greater awareness of tailoring care toward individual differences. Specifically, they were able to recognise SA patients ethnic, cultural and religious nuances. The Caucasian health professionals had specific knowledge about certain cultural and religious aspects, most of which have received media attention. For example, some Caucasian health professionals mentioned fasting *(Int6, F, (C), Diabetes Specialist Nurse (Team Leader), Lines, 153-154),* as a religious obligation.

Health professionals had been informed about religious fasts, specifically Ramadan for Muslims, therefore being aware that the SA population were at high risk during that period. However, more frequent fasting behaviour activities were not acknowledged, (for example, Hindus complete weekly fasts as a reference to please their God). This type of activity was not typically considered in diabetes care. This suggests that Caucasian health professionals were unaware of possible additional and cultural influences.

> *Of my patients I would say that group that's still around forty years age, that have maybe had diabetes for about five years, especially the women, they don't work, they're looking after the elders and they're looking after the youngsters, and it seems to be their health that deteriorates the most, because lots and lots of them are overweight, they're attending weight management clinic as well as the diabetes clinic. (*Int3, F, (SA), Diabetes Specialist Nurse, Lines, 199-203)

Health professionals, specifically those not SA themselves, with less experience supporting SA patients, may be less likely to tailor advice to individual patient needs and subsequently, find it more challenging to support SA patients effectively (e.g. newly qualified health professionals or new to working with high prevalence SA patient populations). Caucasian health professionals relied on informal ad-hoc support from their SA colleagues, for specific guidance about SA patients

> *Just general, really. But like I say, we've got the two nurses here, (name) and (name). (name) speaks a couple of different languages.   We have a new doctor, (name) as well, a new consultant. So we would tend to always go to the people who specialise in SA.* (Int1, F, (C), Diabetes Specialist Nurse, Lines, 481-485)

AND

> *And we have a lot of Asian GPs, and you can learn a lot from them.* (Int4, F, (C), Diabetes Specialist Nurse, Line, 146)

SA health professionals acknowledged that they offered peer-support to their non-SA colleagues.

> *I mean, simple things with working with the team, and explaining to some of the team that they need to go on cultural awareness training, and to understand some of the science behind, or the differences behind the Asian population and the Caucasian population, say around BMI being different for Asians and Caucasians, waist circumferences having a different consequence.* (Int4, M, (SA), Diabetes Specialist Nurse, Lines, 171-174).

There was recognition that SA health professionals have better insight into SA patient needs, and these health professionals used this insight to influence service planning.

> *Or (link worker), she knows the community really well. So she knows that there had been a big wedding or something. You know, she often says 'Well, there wouldn't be...you know, I know there's not as many people will come.' You know, we don't run things generally through Ramadan because again people are less likely to come and don't have the energy to take on board additional education.* (Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, Lines, 505- 511)

The Caucasian health professionals indicated they relied on SA colleagues; some reported to use link workers to overcome specific language barriers. However, one link worker was interviewed and suggested that she was confident within the community she had the most access to, suggesting that as some SA communities are small in some cities and towns, this can create pre-conceived perceptions about those sub-groups.

> *I feel like Pakistani community are more not taking things on board than Gujarati maybe. I don't know. And then the Bengali, because it's a small community in Preston, Bengali. You don't come across so many Bengali, but then yes, it's a bit hard to reach group as same as the Pakistani, but because we do run Urdu courses for the DESMOND as well, and then, because I*

> *speak Gujarati and Urdu, but I don't speak Bengali and Telugu, but then people who speak Bengali, they would probably understand Hindi or Urdu. But we don't really get many Bengali speakers coming, but we do have some small community. I think they're a bit more hard to kind of reach group maybe, or maybe they're not very, I don't know how to put it. But I think, you know, they have different belief and different kind of way of thinking, don't they?* (Int7, F, (SA), Diabetes Link-worker, Lines, 211-219)

Some health professionals reported a lack of any formal training or education regarding SA culture and were unclear how they should tailor advice for SA patients *(e.g. Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, Lines, 620-622)*. Some individuals had independently sought out additional cultural training and support from peers.

> *No. Other than you need to have the knowledge that they're more at risk earlier. You're looking for a different waist circumference. Because if you look at a Bangladeshi lady, they're all very petite, very slim, but if you do a waist measurement, they're always in the at-risk bracket. But I'd like to think I've done a lot of training around this because this has been, sort of east Lancashire has a high Pakistani and*

> *Bangladeshi population, so I have gone to a lot of lectures and done a lot of training.* (Int4, F, (C), Diabetes Specialist Nurse, Lines, 141-146)

Core category: Delivery of Diabetes Care

All health professionals reported they were confident providing basic diabetes advice to their patients. However, those health professionals working within primary care, specifically practice nurses, did identify limitations in their knowledge. They regularly sought guidance and support from DSNs in secondary care.

> *We get a lot of phone calls from practice nurses. 'What shall I do then, shall I try this tablet or this tablet? What do you think is the best?' And we help them as much as we can.* (Int1, F, (C), Diabetes Specialist Nurse, Lines, 289-292)

Health professionals who specialised in diabetes, for example, DSNs highlighted the variation in the advice given to patients from other health professionals, who were not specialists (*Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, 110-112*). They acknowledged that patients could misinterpret information. However, other non-specialist health professionals could improve their knowledge and clinical skills in diabetes management.

> *…medication mistakes are common, really common. Even at the hospital they often prescribe Metformin at*

> *breakfast and bedtime because it’s twice a day. But it’s no use at bedtime. They don’t eat nothing at bedtime. So even the hospital do it wrong sometimes.* (Int1, F, (C), Diabetes Specialist Nurse, Lines, 136-140)

The DSNs were also able to reflect on the diabetes delivery model not always being most suited to the patient’s needs.

> *I don't feel, though, that they get the right education perhaps, at the right time. That doesn't mean that they don't get the right education, but sometimes the timing's not quite right. Because we see patients after say ten years of being diabetic who we give information to, and they say to us, "I wish I was told that earlier", or "I wish I was told that when I was first diagnosed". I'm surprised that that's not what they were given, but perhaps it was in the context where they couldn't understand it.* (Int5, M, (SA), Dietician (Service manager), Lines, 27-32)

AND

> *I mean obviously, people should be getting good quality advice on diagnosis and ongoing in their annual reviews and regular checks in primary health care. What they get is very variable in our experience. There are some people who had got excellent care where they got very excellent knowledgeable staff who are supporting them on a regular basis, but not everybody has that.* (Int2, F,

> (C), Diabetes Specialist Dietician/ Diabetes Education
> Coordinator, Lines, 77-82)

Previous studies have acknowledged that when patients do not speak English as a first language, or at all (Rhodes & Nocon, 2003), a ‘language barrier’ exists, which hinders the quality and delivery of care. This issue is not specific to diabetes and applies to any patient-health professional relationship (Ali & Watson, 2017; Sokal, 2010). This language barrier is assumed to be mitigated by providing a ‘link worker’ or translator services.

> *The main problem I think is sometimes language barrier. Because if we’re saying that diabetes is quite a difficult thing to get your head around, it makes it even more difficult if you’re having to use language line. So I have to tell somebody down the phone they’re then tell…I pass the phone to a patient. They talk. It’s really difficult to get complex information across using a telephone interpretation thing, so that is tricky.* (Int1, F, (C), Diabetes Specialist Nurse, Lines, 350-357)

Language barriers impacted on the delivery of care that health professionals provide and appear to influence patient’s engagement with services (*Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, 484-487*). However, language per se is not necessarily the main issue. Understanding the complex language associated with diabetes itself may override the foreign language issue:

> *At one time, you could say, "Well, yes, it's a language barrier, it's a culture barrier". Our consultant speaks Urdu. One of our other consultants Hindi, I speak Gujarati, one of our nurses speaks Urdu and Gujarati, so language isn't the problem. Access to the materials isn't the problem. It's that group of people that we still find it very hard to get compliance, concordance with medication, and the ability to make the changes.* (Int3, F, (SA), Diabetes Specialist Nurse, Lines, 213-217)

Patient's interpretation of information and the way in which information is communicated varies greatly. Previous research has acknowledged how subtle differences in spoken language (a variation on words in the same language) can influence patient acceptance, understanding and adherence to advice (Ahmed, Abel, Lloyd, Burt & Roland, 2015; Ali & Johnson, 2017). Where language itself differs, between health professional and patient, the translation process of information may alter important aspects of the message (Hull, 2016; van Rosse, de Bruijne, Suurmond, Essink-Bot, Wagner, 2016), as has been described by the health professionals in this study. Moreover, when language barriers and cultural influences of the patient's lifestyle are combined, this appears to create additional confusion, which interferes with the patient's perceptions and understanding of diabetes and the advice they have received.

> *Language, yes, because a lot of the GPs in the area are Caucasian and a lot of the trainers in terms of your*

> *dietary advice or your nurses are Asian -- are not Asian, sorry. So when they're talking about diet it might not be in the same context as them, or they'll politely nod as -- as many people do where they don't understand anything, they're just kind of continuing with -- and you -- you think they're understanding and taking everything on board, but they're just not. So the language is a big barrier. I think because of the cultural differences people haven't really tweaked that the food aspect for -- in Asia culture is huge --* (Int10, M, (SA), GP, Lines, 253-261)

Core category: Patient understanding and engagement with diabetes care

Self-management is primarily carried out by the patient on a daily basis; it is ideal that the patient adapts their lifestyle by incorporating the self-management advice. However, SA patient’s knowledge, attitude and experience influences of self-management behaviour were perceived to differ. It is vital for health professionals to have awareness and insight into cultural norms and ethnic variations in lifestyle behaviours so that the appropriate personalised and tailored advice can be provided. Overall health professionals were familiar with gaps in their knowledge and understanding of SA patients with regards to diabetes self-management, and how they compared with Caucasian patients.

Sub-category: SA knowledge of diabetes and influence towards engagement

All health professionals reported being confident in providing diabetes advice. However, some health professionals felt that they could benefit from learning more about the dietary aspects of self-management, gaining a more comprehensive understanding of cultural influences on eating habits, insight into religious and broader health needs. Providing personalised centred care in the SA context can improve patient-provider communication leading to patient satisfaction and adhering to advise.

> *I think it's (health professionals require a) better understanding of how does of culturally (cultural) and religious influences (impact) are on their (SA patients) eating behaviour, and (would benefit from) more knowledge about fasting is certainly good.* (Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, Lines, 670-679)

AND

> *And it's what -- what can we do to reduce the stigma around diabetes, what can we do to make them get better and their health beliefs to a large extent as well.* (Int10, M, (SA), GP, Lines, 462-464)

The health professionals noted that, due to inconsistent advice offered, patients made sense of the information by discussing with friends and family. Often patients described misunderstandings to health professionals demonstrating how confused there were.

> *You tend to have to do a myth buster rather than...People in both cultures think when on insulin's the end of the road, they think it's progressed to an end stage, so I'd say the key questions are myth busting.* (Int4, F, (C), Diabetes Specialist Nurse, Lines, 66-69)

The health professionals identified some contributing factors, which influenced self-care in SA compared to the Caucasian patients.

> *In the Asian community, we got a lot of people who get told you can't… you shouldn't be eating rice.' So, there's often a lot of very specific information that comes out which influences what people understand really.* (Int2, F, (C), Diabetes Specialist Dietician/ Diabetes Education Coordinator, Lines, 132-135)

AND

> *Some people believe in the will of Allah, which is one of the reasons I work very closely with the Imams because he gives me a quote to quote back of them. I don't know if that's any different to a Caucasian who's...It's perceptions of health, isn't it?* (Int4, F, (C), Diabetes Specialist Nurse, Lines, 171-173)

5.5. Discussion

Previously there has been a paucity of research examining health professionals' attitudes towards diabetes self-management in SA. Findings from the present study showed that both patient's and health professional's own ethnicity influenced their perceptions towards T2D self-management and health care. These conclusions are based on health professional's experiences and reflection of supporting SA patients. For example, SA health professionals in this study suggested that: SA patients did not have a sound understanding of diabetes; that the Caucasian population were less tolerant to being ill overall, compared to SA patients which meant they would be more likely to seek or implement advice offered. In contrast Caucasian health professionals were less likely to identify individual barriers but were more likely to suggest that SA patients were difficult to treat due to (foreign) language barriers. This suggests that health professional ethnicity influenced pre-conceived ideas about population groups, therefore influencing the delivery of care. In the SA population there are multivariate languages, therefore instead of focusing on simply translating the information from English to the different languages, there needs to be a focus on translating the information to the cultural needs of that population.

The results revealed that health professionals reported lack of culture-specific training (Rosenberg, Richard, Lussier & Abdool, 2006; Wachtler, Brorsson & Troein, 2006; Watt, Abbott, & Reath, 2016) and as a result, this lack of knowledge perpetuated certain misconceptions of the SA culture. This informed their perceptions and experiences of diabetes delivery and in supporting the SA patient groups (Cortis, 2004; Fagerli et al., 2005).

Health professionals typically had not received culture-specific training and as a result, lacked the knowledge to help them personalise patient care relevant to their SA patients cultural and ethnic needs. Language barriers may be referred to as a communication delivery issue (Alam, Speed, & Beaver, 2012; Dickinson, Guzman, Maryniuk, O'brian, Kadohiro, Jackson, et al., 2017; Rhodes & Wright, 2003). However, the issues of delivering complex self-management and disease-specific advice and information appear not to be about merely transferring spoken words from one language to another. When translation services and language interpretations are used as such mitigating their actions, and therefore health professionals are limited in their approaches. Often the other underlying psychological issues (such as diabetes is considered a social norm, Social Norm Theory (Perkins & Berkowitz, 1986) are not discussed and consultations remain focused on translating simple T2D advice only. In these circumstances, patient's needs are not addressed holistically which impact on patient engagement (Dickinson, 2017). Considering the range of employment from 3-40 years, this suggests that cultural constructs into diabetes care and education that targets ethnic groups may result in greater patient satisfaction, engagement and clinical outcomes.

Although numerous qualitative studies have explored health professionals' views, (Capell, 2008; Cortis, 2004; Fagerli et al, 2005), attitudes and perceptions of patients and adherence to diabetes management (Banni-issa et al., 2015; Clarke & Hampson, 2003; Torres et al., 2010; Wens et al., 2005), there is a paucity of research exploring health professionals' views on diabetes management in SA patients specifically. The four studies that have investigated SA patients, have looked specifically at one sub-group: for example, Hawthorne et al. (2003) studied a Bangladeshi participant group, Cortis (2004) and Fagerli et al. (2005) focused on Pakistani patients and Capell (2008) carried out a quantitative study to assess cultural competency. SA population sub-groups posses' various attitudes, beliefs and values related to health, making the development of cultural competence specific in this care in SA patients is essential for every healthcare provider. Therefore, this study contributes to gaining an insight into how health professionals understand (or not) the diverse, heterogeneous nature of SA T2D patients.

Numerous studies have documented how cultural factors influence self-management in the SA population (Greenhalgh et al., 1998; Jepson et al., 2012; Lawton et al., 2008). The SA population have many sub-groups, and each sub-group has their own cultural needs that need to be taken into account when health professionals are providing care. To date, there is a growing body of literature documenting that when health professionals understand a patient's needs, it leads to active patient adherence. For example, Choudhury et al. (2009) found that patients prefer to be treated by health professionals of the same ethnic group. The current study lends further support that there is a lack of cultural knowledge about specific ethnic needs by health professionals and there is a need to support them to understand these better.

As diabetes is a multi-faceted and complicated condition to explain, monitor and manage variation in health professionals delivery, understanding and subsequent communication with patients exists, regardless of culture, religion or ethnicity (Avery, Charman, Taylor, Flynn, Mosely, Speight, et al., 2016; Rushforth, McCrorie, Glidewell, Midgley, & Foy, 2016; Yach, Stuckler, Brownell, 2006). However, in addition to these generalised issues, there are specific problems associated with the delivery of diabetes for SA patients, as also recognised in previous literature (Mukhopadhyay et al., 2006; Negandhi, et al., 2013; Soljak, et al., 2007). There is some attempt to adapt care towards SA patient needs, e.g., but often such adaptations are simply limited to issues of (foreign) language interpretations, rather than the more complex issues this study has highlighted (Khunti, Kumar, & Brodie, 2009; Marwa, Mughal, Sunsoa, & Bibi, 2004). Specific advice is needed to be tailored to the SA culture, such as culturally relevant dietary advice (Marwa, Mughal, Sunsoa, & Bibi, 2004).

Qualitative methods were appropriate for this study, allowing the researcher to explore behaviours, interactions and attitudes. There are a number of health models (HBM, (Rosenstock, 1974) TTM, (Prochaska & DiClemente, 1986) and TPB, (Fishbein & Ajzen, 1975)) that have been developed to explain health behaviour. Although these lack cultural sensitivity, the GT framework presented in this study (*Figure 5.2*) advances our understanding of diabetes self-management in SA T2D patients, over and beyond traditional health behaviour models. For example, models like the HBM (Rosenstock, 1974) fail to account for social factors that may impact on a patient’s self-management behaviours, such as the attitudes of health professionals. The current framework is unique and superior in this respect.

The researcher had not expected cultural issues to be such a principal finding within this analysis. The unique element of the new GT framework (*Figure 5.2*) suggested that integrating psychological constructs (such as tackling an individual's health beliefs of T2D with reference to social norms and incorporating religion) could help to understand the importance of religious behaviours. Investigating health beliefs alongside religious, and social-cultural factors would offer more meaningful and personalised care to patients. Current practice suggests that health professionals offer standardised advice, and for example often advise patients not to participate in religious obligations (which promote variation in food consumption and thus impact on T2D outcomes), such as fasting behaviours. However, in doing so, such advice is considered a disconnect from the patient's daily lifestyle, religious and social-cultural world. For example, Lawton et al. (2008) reported that SA communities religious and cultural behaviours are influential and central components to an SA individuals everyday life. If a person is seen (within the SA community) as doing something out of the norm (i.e. not fasting abiding to religious requirements) the person is judged, and fears of becoming isolated and singled-out manifest (moved into 'out-group'), such fears may supersede any healthcare advice offered by the health professional and thus impact on lifestyle decisions. Understanding patient individual needs, alongside religious and social-cultural influences, and integrating these aspects into practice could help elucidate communication barriers. This could be achieved by health professionals receiving culture-specific training (becoming more familiar with SA subgroups variations) and integrating psychologically informed diabetes delivery.

Few studies have examined health professionals' attitudes towards diabetes self-management in SA patients. The findings from this study demonstrate that ethnicity plays a key role in influencing patient's self-management, specifically in the SA population. The analysis identified that there are behaviour and lifestyle differences in population groups that influence self-management behaviours, and some health professionals were able to recognise this specifically. However, this study revealed that the ethnicity of the health professional themselves, and that health professionals experience of working with SA patients, also influenced their pre-conceptions of their SA patients, thus, in turn, affected healthcare delivery and advice they offered to this population group. There is a need for better knowledge of the SA population to help health professionals identify ethnic, social-cultural and religious variations in lifestyle and behaviours. Health professionals' experiences, attitudes, knowledge and beliefs regarding patient's ethnicity, alongside the patient's communication and interactions, consequently shape the health professional's diabetes delivery and subsequent patient self-management behaviours.

5.5.2. Future Research

The following recommendations for further research are made as a result of the findings of this study:

Develop a training programme for health professionals, promoting health psychology techniques to help better understand a patient's perspective and enable them to use different communication methods into practice. This GT framework could be tested with other participant groups to help validate the framework. Another avenue of future research could be to conduct a focus group with health professionals and patients to discuss possible changes to improve care. Finally, the findings from this study indicate that there are issues with communication between health professionals and SA patients. However, there is a need for further exploration. Therefore, the next study will interview SA people with T2D to explore their perspectives to see if they echo some of the themes emerging from the findings of this study.

5.5.3. Strengths and limitations

This study has expanded previous research by examing health professionals ethnicity, which past research has not explored. Previous research has focused mainly on the job role of the health professional. Indeed, this is important. However, accounting for health professionals ethnicity and the hours of culture-specific training undertaken allows individuals to gain a deeper understanding of their perception towards culturally tailored care. Upon reflection, health professionals were nervous in discussing knowledge relating to ethnicity, culture and religion. This was perceived as a sensitive topic, the interviewer was SA, and as such, the Caucasian participants needed some reassurance and examples of feedback from other participants to aid the flow of the interviews. It is acknowledged that the recruitment strategy was a snowball methodology and based on theoretical saturation (Strauss & Corbin, 1998) of data. However, as the participants acknowledged their own years of experience in their development as a successful communicator with SA patients with diabetes, it could be plausible to expand recruitment to those in training, or very newly qualified health professionals who may have minimal experience of working with SA patients with diabetes.

5.5.4. Conclusion

The qualitative research has provided insight into how health professionals can be better prepared to deliver care to the SA population if culture-specific training was available, as this would reduce cultural bias perceptions that can be applied to the patients. Developing a culture-specific training programme will allow the health professionals to gain knowledge and skills in caring for ethnic minorities by gaining insight into the cultural and religious differences, as this would benefit the health professional in addressing patient needs.

5.5.5. Key points from this study

- Overall, health professionals were very knowledgeable and experienced in general diabetes care. However, they reported a lack of knowledge regarding ethnic and cultural differences in SA populations, and as such, this influenced their communication with the SA patients.
- The ethnicity of health professionals affected the delivery of care, ultimately influenced SA patient’s interpretation of medical advice and engagement in self-management behaviours
- (Foreign) Language was seen as a barrier to providing effective care. However, understanding patient needs by promoting effective

communication (rather than language) may improve engagement and clinical outcomes.

Chapter 6: Study 2- A qualitative study exploring cultural factors in T2D self-management amongst SA patients

Study 2 - Chapter Overview

While study 1 (*Chapter 5*) provided an insight into health professionals perspectives of T2D diabetes self-management, there is a need to explore patients perspective further, to understand better their needs for improving diabetes self-management. The present study aimed to explore this gap in the literature, by exploring the ethnic, religious, and related experiences of SA patients receiving NHS diabetes care.

This study completed 17 semi-structured interviews, focusing on people with T2D from the North West of England (Bolton, Preston, and Blackburn). The study employed GT methodology, analysis and sought to reach theoretical sampling to produce a framework (Strauss & Corbin, 1990).

This chapter presents a GT framework which consists of one core category patient centred care, which is informed by the interaction of the following three categories: 1) Psychological distress and communication; 2) Behavioural outcomes: ‘I'm not always successful, but I will try to do that, just eat less', and 3) Influencing variables take priority: ‘I think that's more your religion'.

To improve diabetes self-management amongst SA patients, healthcare professionals (and services) need to integrate more specific and considered person-centred care into practice. This study highlights that it is important to distinguish patient communication needs (beyond that of foreign language assumptions). Whilst health professionals try to offer personalised care to all patients, currently, for SA patients, in particular, their individual needs which relate to ethnicity (social-cultural identity) are often not considered by the health professional and, as such this impacts patient’s perceptions of their health professional, the clinical advice offered, and subsequently these perceptions appeared to impact on the patients interpretation and application of T2D self -management behaviours. This finding is especially important given the heterogeneous nature of the SA population and highlights the need for health professionals to investigate and explore ethnicity and social-cultural religious influences individually with each patient, rather than making assumptions or not considering such aspects.

6.1. Introduction

The previous literature review and meta-synthesis (*Chapters 2 & 3*) have documented a detailed account of the evidence which has formed the basis of this study to explore the psychological factors that influence self-management behaviours towards T2D diabetes in SA patients. Having examined health professionals attitudes (*Chapter 5*), it was necessary to look at patients' perspectives to see if the emerging framework echoes some of the themes.

Government policies have tried to tackle health inequalities (Exworthy, Blane & Marmot, 2003; Smith & Kandlik Eltanani, 2014). Although ethnicity has not been a consistent focus within this, understanding cultural variations and attitudes are needed for effective healthcare to be delivered effectively (Napier, Ancarno, Butler, Calabrese, Chater, Chatterjee, et al., 2014). Such differences can affect a patient's expectations; their expression of symptoms or condition understanding; family acceptance and interpretation of the condition. However, as explored in study 1 (*Chapter 5*) health professionals do not appear to fully address and respond to patients cultural, religious or ethnic needs or beliefs. It is important to explore this topic from a patient's perspective to better investigate how they experience and interpret T2D advice offered and how their culture, religion and ethnicity may influence their T2D self-management behaviours as previous evidence suggests that ethnic minority groups in the UK have worse health outcomes than Caucasian patients (Bhopal, 2013; Sattar, & Gill, 2015; Modesti et al., 2016).

6.1.1. Aim

To explore SA patient's experiences of diabetes self-management and consider their psychological understanding and needs, from the multiple ethnic and religious perspectives inherent in a heterogeneous SA population.

6.2. Methods

6.2.1. Design

A qualitative study using semi-structured interviews and GT analysis (Strauss & Corbin, 1990). GT methodology supports the development of a framework highlighting SA patient's key issues of diabetes self-management.

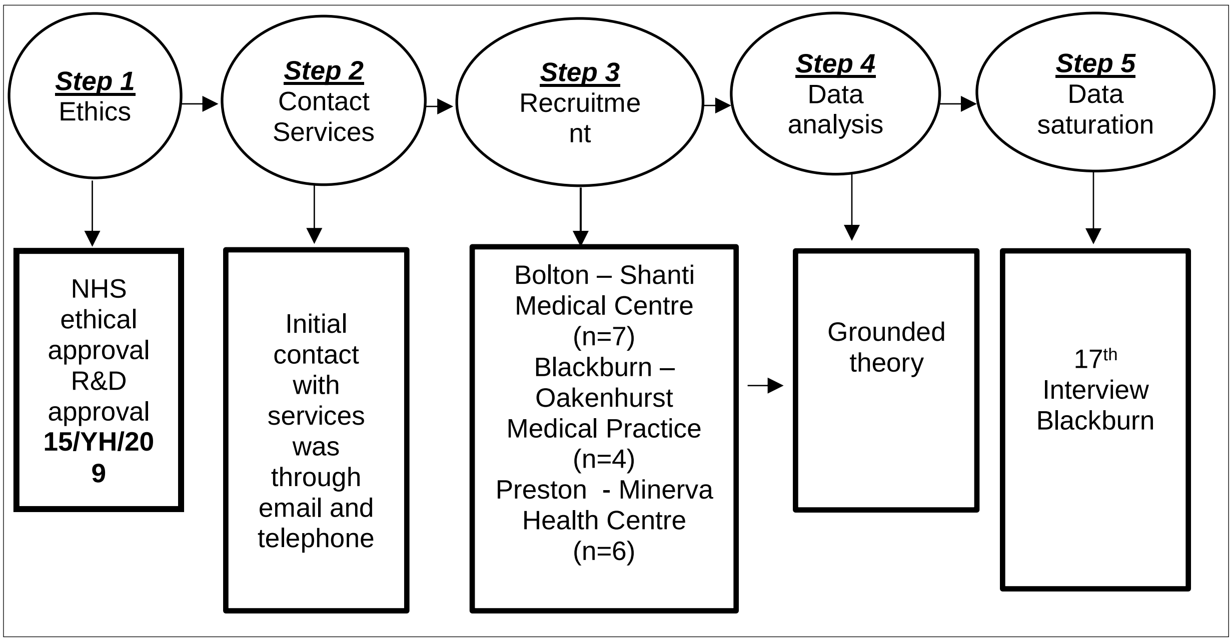

Figure 6.1: Overview of study methodology

6.2.2. Initial Purposive Sampling

Patients registered at health centres and general practices in Bolton, Blackburn and Preston were recruited into this study. Various health professionals, working within diabetes care, identified possible patients. Patients were offered a copy of the PIS (*Appendix 6.1*) and asked if they would be interested in taking part. If a patient expressed an interest, the health professional passed on the patient's contact details to the researcher, who subsequently made contact to discuss the study and arrange a convenient time for the interview.

Theoretical sampling (*Table 6.1*) and purposive sampling aimed to recruit a sample that was diverse regarding gender, ethnicity, religion and duration of diabetes as reflected of the local population (*Chapter 1, page 39 – sub section 1.3 for definitions and characteristics of the population in recruitment area*). In line with GT, the initial interviews were analysed simultaneously to data collection. The researcher used this initial analysis to inform the recruitment strategy to seek specific patient demographics of whom to recruit next (*Table 6.1 + 6.2*). Recruitment of participants commenced until theoretical saturation occurred (Strauss & Corbin, 1998).

Table 6.1: Evolution of theoretical sampling and interview questions

The first three interviews were conducted with a family of three. The interviews conducted gave an understanding of how support from their family members and regular check-ups from their health care team who would be on the ball by sending appointment letters had a positive impact on allowing the patient to make the right choices in aiding their diabetes management.
The participant recruited for the fourth interview had diabetes for many years, this participant had adjusted their lifestyle to improve their diabetes management, but it was trial and error with the choices made. In the beginning, lack of knowledge and awareness of the effects of what diabetes can do the body, so the early care was not correctly received.
The fifth interview was interesting as the participant had been diagnosed with T2D at a young age, it was interesting to see how the participant changed their habits and how this was achieved, fear of insulin instantly made the participant change their lifestyle, and now the participant has gone from being on insulin to diet controlled diabetes. The participant admitted it was difficult but doable with support from family and his health care team.
The sixth interview revealed some interesting data, this participant also had mental health issues, and this was found to really hinder diabetes management. The participant found the balance really difficult especially as the care was split between two different teams and there was no communication between the diabetes team and the mental health team. This participant revealed that they did not receive the advice and guidance during the initial stages of diagnosis. This interview suggested that religion does not play a role.
The seventh interview was with a participant who attended the DESMOND programme and still said, although it was useful, it would have been good if his wife would attend as she does the cooking, he also said he preferred if Asian health professionals were to give him advice as they understand more. He also mentioned how he believed that a herbal remedy had helped him.
By interview eight, a few themes had emerged and needed further exploration; this interview gave additional insight into the role of women in an SA household and how social support influences management. This interview also further clarified the impact of co-morbidities and how they hinder management, for example, some dietary aspects overlapped with other conditions the patient had and the participants were not aware of any coping mechanisms to deal with it. The advice around diet was very vague and hard to integrate. There was also queries into herbal remedies. Religious beliefs were strong for this patient.
At this point, religious nuances still need exploring; it appears that ethnicity and religion can be conflated and can lead to different attitudes in decision-making. The family was highlighted in playing a role.
Interview 10 further clarified the concept of the emotional management that participants are faced with when dealing with co-morbidities such as depression. This interview also highlighted the importance of family and the wider support network that is needed to help self-manage.
The next two interview was with two family members a father and daughter both with diabetes. This interview was interesting as the father had diabetes for a number of years and revealed that the process that he had gone through to get to this point of management was on-going and a number of contributing factors were apparent such as cultural factors i.e. taking part in events, going through the hypo and hypers and understanding the condition and also moving with the time and reflecting on how with time things have changed in their culture such as diabetes being more culturally accepted and people taking that into account when socialising. On the other, the daughter's account revealed that psychological barriers exist from the beginning and healthcare support is required as early as possible. These interviews revealed that religion did not play a role in their diabetes.
In this interview, it was highlighted that religion influences attitudes towards foods, so this patient followed a vegetarian diet. Again, co-morbidities stopped exercising, so coping mechanisms need to be integrated into care.
Interview 14 and 16 were husband and wife; these interviews revealed some interesting findings that family support is important in the SA population, and for this reason, self-management can be neglected. Support on how to deal with family dynamics was an issue as the family came first.

This interview revealed that having good support allowed the participant to have good control. Although there were cultural and or religious factors that were important the participants were able to implement positive coping mechanisms
This interview allowed to reach saturation as the participants further confirmed that religious and cultural nuances exits, medical management is difficult, and behavioural management is hard to integrate.

Overview of participants

Seventeen participants completed interviews for saturation (nine females: eight males; mean age 54, range 35- 73 years). Length of T2D diagnosis ranged from 2 months-17+ years. In line with the principal focus of this study, the inclusion criteria included patients with T2D if they were aged 18+ years and were of SA descent.

Table 6.2: Characteristics of Participants

	Name (pseudonym)	**Age**	**Gender**	**Ethnicity**	**Duration**	**Religion**	**Job Title**	**Area**
1	Omar	56	Male	Indian	2-3 years	Hindu	Unable to work	Bolton
2	Nadia	53	Female	Indian	4 years	Hindu	Homemaker	Bolton
3	Priya	53	Female	Indian	8 years	Hindu	Homemaker	Bolton
4	Zahira	73	Female	Indian	10+ years	Muslim	Homemaker	Bolton
5	Zain	35	Male	Pakistani	15+ years	Muslim	Employed for wages	Bolton
6	Haroon	60	Male	Indian	14 years	Jahowas Witness	Retired	Preston
7	Mahir	47	Male	Indian	12-13 years	Muslim	Employed	Preston
8	Zaina	46	Female	Indian	3 years	Muslim	Out of work	Preston
9	Safiya	54	Female	Indian	8-9 years	Muslim-	Employed	Preston
10	Samir	56	Male	Indian	17 years	Muslim	Out of work	Preston
11	Yash	58	Male	Indian	4 years	Sikh	Unable to work	Bolton
12	Maha	37	Female	Indian	2 months	Sikh	Homemaker	Bolton
13	Raj	61	Male	Indian	9 years	Hindu	Out of work	Preston
14	Aliza	56	Women	Indian	3 years	Muslim	Homemaker	Blackburn
15	Fatima	57	Women	African	14 years	Muslim	Employed	Blackburn
16	Kamran	63	Male	African	10 years	Muslim	Unable to work	Blackburn
17	Aleena	43	Women	African	6 years	Muslim	Employed	Blackburn

6.2.3. Materials

A semi-structured interview schedule (*Appendix 6.2*) was determined by the topics and issues identified from the previous chapters (*Chapters 2, 3 & 5*). Interviews included open-ended questions (Weller, Vickers, Bernard, Blackburn, Borgatti, Gravlee, et al., 2018) to allow participants the opportunity to explain their experiences fully (*Table 6.3*).

Table 6.3: Interview Schedule

Key Topics
What does looking after your diabetes mean to you?
Have you been given any particular advice about managing your diabetes? Diet Exercise Medication Checking your blood glucose Smoking Alcohol intake
Do you follow the recommended Diet Exercise Medication Checking your blood glucose Smoking Alcohol intake
Do you do this well
In your experience, what issues have you been faced with in managing your diabetes?
Can you tell me about the experiences you have had with following the advice given on managing your diabetes?
Is there any aspect of your self-management you would like more information/support with?

6.2.4. Procedure

In qualitative research, use of translators aims to overcome language barriers. However, the use of translators may elevate methodological challenges such as building participant trustworthiness (Squires, 2009). With this study focussing on SA patients, it was anticipated that there would be various languages spoken by participants. Consequently, the researcher undertook the interviews in languages as appropriate to each participant (Murray & Wynne, 2010), this included Gujarati, Urdu or English. No participant was refused entry to this study based on language spoken.

A PIS was available in the preferred participant's language either (English, Gujarati or Urdu). This PIS explained the purpose and requirements of the study. The participant had the chance to ask any questions or queries, and then signed a consent form (*Appendix 6.3*). Anonymity was discussed, and the participants were advised that quotes could be published, but any personal information would be removed or names replaced with a pseudonym. At this point, the participant was also informed about a follow-up study, and if they wished, they recommended a family member that could also become a participant in another study. The participant filled out a demographic screening form (*Appendix 6.4*) which required information on their age, nationality, religion, length of diagnosis, and employment status. The interviews were all conducted in a private environment, at a location most suitable for the participant (16 home interviews; one at a community venue) taking a mean duration of 18 minutes.

At the start of the interview, the researcher exchanged pleasantries to set the participant at ease and to build rapport (Glesne, 2006). The interviews followed the semi-structured nature of the interview schedule but allowed for flexibility in questioning depending on the response of the participants. Interviews were audio recorded using a Dictaphone, at the end of the interview the researcher switched off the recorder, thanked the participant for taking part, and asked if they had any questions. A debrief (*Appendix 6.5*) was available to read in preferred language (English, Gujarati, Urdu) at the end of the interview.

6.2.5. Reliability and Validity

Eleven interviews were conducted in English and six performed wholly or partly in Gujarati. Audio recordings were transcribed verbatim by the researcher. The audio recordings of the six Gujarati interviews were translated into English by the researcher. For quality checking (Fujii, 2017; Temple & Edwards, 2002; Temple & Young, 2004), a second multi-lingual researcher (an SA male) reviewed the audio and text translations of the six Gujarati interviews to confirm accuracy and written translation, no issues were identified (*See Chapter 4, page 133 – sub section 4.8 for further information on this process*).

6.3. Analytical procedure

The analysis was informed by GT (Strauss & Corbin, 1990) (*For full methodological explanations see Chapter 4, pages 128-131 – sub section 4.7 for further details*). Recruitment was completed alongside the initial analysis, memo writing, and conducting reflective practice with DoS.

In this study, 1222 open codes (*Appendix 6.6*) were subsequently grouped into 27 axial codes (*Appendix 6.7*) with various supporting memos (*Appendix 6.8*). Selective coding, refinement and review supported the development of a GT framework consisting of one core category and three subcategories, which formed the basis of this theoretical framework (*Figure 6.2*).

6.4. Analysis

The core category *Patient-centered care* was informed by interaction of the following three categories: 1) *Psychological distress and communication*; 2) *Behavioural outcomes: 'I'm not always successful, but I will try to do that, just eat less'*, and 3) *Influencing variables take priority: 'I think that's more your religion'*.

6.4.1. GT Framework:

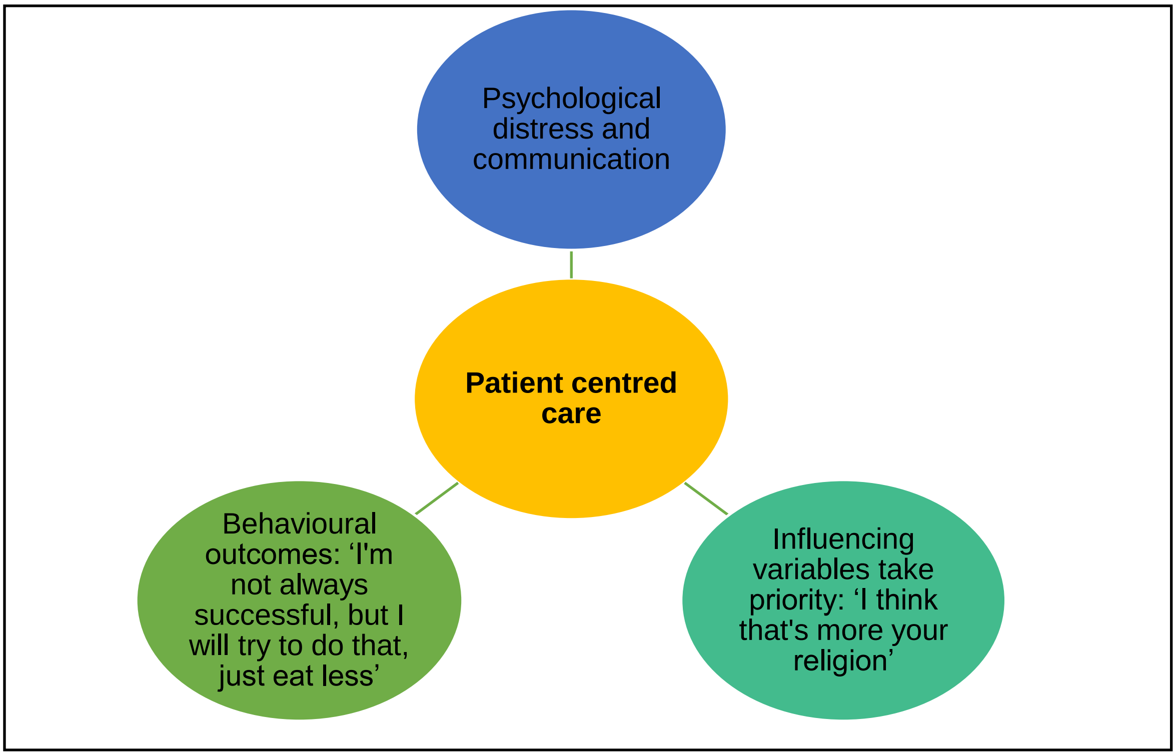

Figure 6.2: Framework of patient centred care

Core category: Patient-centred care

Participants did not recognise that they had received patient-centered and individualised care. They reported the current approach to care, as having a negative influence on their wellbeing, and thus increasing their levels of psychological distress.

Participants interpreted the expectation to ‘self-manage’ their T2D independently, as a ‘lack of support’, as opposed to feeling empowered to do so by their health professional. No standard ‘approach to care’ was described by participants and considerable variation in initial and on-going care was described. Participants had a strong sense of isolation and referred to a ‘get on with it’ attitude promoted from their health professionals; these messages were interpreted as a lack of care, support, advice and understanding or knowledge on the part of the health professional.

> *I think they need to talk more to me about it, rather than just saying you're doing well when I go for a yearly check-up. The doctor just says I'm happy with your results, and that’s it* (Interview 6, Lines, 82-83).

Subcategory: Psychological distress and communication

For many participants, their GP confirmed the diagnosis of T2D. For some participants, psychological concerns were apparent at this time, but the health professional did not explore such difficulties. As documented with other health conditions, e.g. inflammatory bowel disease (Kluthe, Isaac, Hiller, Carroll, Wine, van Manen, et al., 2018) the diagnosis was described as a ‘surprise’, and participants referred to shock, disbelief and feeling ‘depressed’. Thus, they found acceptance of T2D difficult, and such psychological distress interfered with their receptiveness to new information and their ability to make appropriate lifestyle changes.

> *I was very depressed. I just thought, when I got told, I was just like, "Oh God". I came home, and I was quite shocked*

> *actually because I would never have expected myself to be diagnosed with diabetes, because I've never, well, I'm not saying I'd never have the condition or anything like I never had any symptoms. So when they came in, and they told me, I was just like, "Oh, right, ok then", and I came home, and I just started crying. Yes, I just started crying. I was just thinking, "Oh no, what's happened now?" Well, not what's happened now, but in a sense that having that condition, it affects you, doesn't it?* (Interview 12, Lines, 168-174).

Participants felt it was important to consider a patient's psychological needs and understanding during diagnosis and beyond. Participants reported a lack of overall support and understanding of their condition.

> *Disappointed really. Quite disappointed, because you try to manage the condition yourself. I think it's too much for someone to take on if they're newly diagnosed with it. I think there should be more support available. I'm not quite sure what kind of support there should be, but maybe from the nurse that you can go and see* (Interview 12, Lines, 80-83).

Participants summarised their health professional interactions as 'biological', whereby their appointments were considered basic and practical. None of the participants acknowledged how their emotional needs had been assessed or considered in their management plan. NICE guidance (2015; 2017) recommends 'structured patient education' for all T2D patients, to support them to make lifestyle behaviour change, and engage in effective T2D self-management. However, many expressed strong concerns that they had not ‘been offered’ or received any formal, structured education (e.g. programme such as DESMOND or EXPERT Patient). Many reported that they had learnt to manage from ‘trial and error’ with ad-hoc support from health-professionals following routine check-up appointments. While these participants may have received one-to-one support, they did not perceive the ‘education' to be adequate or as expected.

> *…my practice nurse, because she just gave me a sheet, basically, a leaflet saying, "This is what you need to do", not need to do, just some guidelines and advice, and I was like, "All right, that's it’* (Interview 12, Lines, 106-108).

Additional NICE guidance (2011) also recommends that all adults with diabetes are assessed for psychological problems. Yet, participants described a lack of psychological assessment and support. The participants were able to reflect on how their T2D influenced their emotions.

> *Yes. I notice when my blood sugar is high, I just don't want to talk to anybody. I feel really down and depressed, and I just want to be left alone and stuff* (Interview 17, Lines 68-69)

In addition, they recognised how their emotional responses influenced their T2D management behaviours.

> *Sometimes when you get hungry, you cant help but eat something with sugar, when you sugar goes low you eat too much sugary stuff* (Interview 10, Lines 18-19).

When participants were able to describe positive interactions with their healthcare provider (often perceived to be receiving proactive contact from their health care provider), they acknowledged how these encounters influenced their own wellbeing and reduced their psychological distress. Moreover, when participants were able to reduce their distress, they reported better subsequent self-management (e.g. attending appointments; making additional lifestyle changes). This was aided by the perception of better health professional support and social support via friends and family.

> *Yes, and all that. I was very, very pleased that somebody came out and helped me around, but I'm very, very happy with my GP, which have sent me down for the classes, which I did go for the course. Yes, and that helped me a lot. I'm controlling my diabetic, which the result they've just given to me yesterday. It came out good. She was very happy with it* (Interview 14, Lines, 177-180).

Subcategory: Behavioural outcomes: 'I'm not always successful, but I will try to do that, just eat less.'

Participants perceived T2D as complicated, which commanded a complex management regime. Participants reported a sense of isolation and psychological distress throughout their diagnosis period. However emotional concerns, as discussed here, are not unique to SA patients. Previous literature has highlighted that psychological distress is common in patients with T2D as the demands of the management can lead to emotional distress (Berry, Lockhart, Davies, Lindsay & Dempster, 2015; Sturt, Dennick, Due-Christensen, & McCarthy, 2015). However, in addition to such T2D distress, SA patients appear to experience increased communication difficulties. In particular, SA participants referred to a lack of personalisation from health professionals. They reported that health professionals referred to their communication needs, purely relating to (foreign) language barriers. Therefore, participants felt that their consultations had been overly simplified as a result. In turn, participants believed this process reduced the quality of care they received, in essence not receiving detailed support but basic information only.

> *Nobody really gives me advice, when I went to the doctors they had information there, and they advised me from there what I should and shouldn’t eat so I just stopped eating what I shouldn’t* (Interview 4, Lines, 26-27).

> *Only the advice that I got from the DESMOND course that I attended recently. Before that, the doctor just said to me just eat half, only half of what I am normally eating, so I've tried to do that. I'm not always successful, but I will try to do that, just eat less* (Interview 6, Lines, 5-7).

In line with NICE recommendations (NICE, 2009; 2015), all patients should have access to structured education. Not many participants acknowledged being offered or indeed attended an education programme. For those that did report participating, they had either sought out the course themselves or coincidentally found out about it. Health professionals typically placed blame onto patients, for lack of T2D understanding or non-attendance at education programme. However, these findings suggest complexity (and variation) around the communication of such education offers.

> *I just happened to ask the nurse. I said, "Is there anything I can do for my diet?" And she referred me to the DESMOND course* (Interview 6, Lines, 22-23).

AND

> *I contacted her through a friend. She was doing the Desmond programme, and I said I wanted to know* (Interview 9, Lines, 12-129).

Self-management is a term used to include all the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the health care system (NHS England, 2017). Response to self-management can vary across patients, and the concept of self-management may not be entirely understood as definitions, understanding and expectations of self-management can be basic. There was an unresolved conflict between the health professionals' expectations of a patient to take responsibility for their diabetes and conduct comprehensive self-management behaviours, compared to the patient's interpretations of T2D self-management advice behaviours. Interpretation of advice led towards behavioural outcomes which became unmanageable long-term.

> *I think I'm quite disciplined, but sometimes if I'm just craving it one day like I want a chocolate cake, I'll just go for it because I just think I can't. What it is, I think for six weeks, five to six weeks, I was really good. I was just like, "I'm not having any cake, I'm not having any chocolate", and then I just cracked. So then I just thought, "Do you know what? I'm treating myself. I'm going to have a chocolate cake"* (Interview 12, Lines, 137-141).

In reality, self-management behaviour was perceived as prescriptive and basic, which did not account for the individual patient needs (e.g. dietary advice offered was generic and overly simplified). SA patients did not believe their SA cultural diet had been considered in relation to T2D advice. The generic information did not help them make sustainable changes to their diets. However, some participants were able to describe changes they had made relevant to dietary behaviours, suggesting that at least some of the advice received had been useful.

> *No, I still eat Asian food, but I try to have it with less oil, low carbohydrates and I try to cut down on stuff like that, like without sugar tea I use sweetener* (Interview 7, Lines, 38-39).

AND

> *Yes, I still do eat it but now what I do when I sit to eat is that I take out a portion of food and that is all I eat, I don't eat anything less or anything more just that portion, that makes it easy for me to control. In curries, I have reduced the oil and salt* (Interview 10, Lines 73-75).

Participants reported variation in experiences about the practice of SMBG. Many participants reported uncertainty, lack of knowledge or feeling scared of conducting SMBG. There appeared to be inconsistency in advice and application of SMBG. Which created confusion:

> *I haven't asked for one (blood testing kit), but the thing is that if I do that, it sort of will make me go what do you call it? Frantic, that if my sugar level is going up or down, and every day I'd keep an eye on it and all that, it's just on your mind then, that your sugar levels* (Interview 15, Lines, 73-75).

Subcategory: Influencing variables take priority: 'I think that's more your religion.'

More specifically, participants reported the advice provided from health professionals was deemed 'generic', not culturally specific or acceptable to their cultural family lives. Generic dietary guidance such as the 'Eat Well Guide' disengaged participants. They did not feel this information as relevant to them. Hence their diabetes self-management in relation to their diet became less of a priority, over their culture and religion.

> *No. I haven't had any advice on Asian foods at all, because even the diabetes clinic, the course that I went to, it was just a generalised how the system works and what happens if you break down, and how everything functions and things like that. And they just show you what kind of oils, and the contents of how much sugars there is, and what's good for you and what's bad for you, but they didn't actually have a programme where it covered our everyday food, like in the rotis and the chapattis that we make, and all the curries that we make. What should be put in, what shouldn't we put in? What should we be using, how much sweetness would it have if we put this in, or how much sweetness would it have? Because I can't assume how much sugar there is in because I was quite shocked when I went to the course as to how much sugar some of the things had. We just put a few cubes, and it was quite a lot of cubes or sugar, and I just couldn't believe it, you know, as to how much sugar it had* (Interview 8, Lines, 30-41).

Religious diversity (e.g. Hinduism, Islam, and Sikhism) exposed additional nuances within the SA sub-group of participants. This influenced their T2D behaviour (e.g. dietary practices), which further varied between individuals. It is important to have an awareness of these religious (e.g. dietary) nuances as the response to the type of (nutritional) advice varied amongst the different SA sub-groups.

> *We don't take any meat, fish or something like that. We don't take any. But it doesn't affect any of my diets, you know Yes* (Interview 13, Lines, 65-66).

Individual's religious beliefs and behaviours adopted as a result of their religious obligations had an impact on advice and subsequent self-management behaviour. For example, Sikh participants were open-minded towards health, acknowledging key health messages and reflecting on the acceptance of westernised lifestyle and health advice such as ‘cutting down oily food'. However, there is evidence to suggest that fasting (which is a religious requirement for Muslims), has a significant impact on diabetes management (Patel et al., 2014). However, some nuances exist within this specific group and how they respond to health-related information. Some felt that diabetes self-management had no relevance to religion and would prioritise their T2D management (e.g. not participate in fasting) this was most prominent in the African participants. In contrast, other participants (specifically, Muslim) held strong religious beliefs which would over-rule their T2D management, as such fasting behaviour would take priority, and potentially be detrimental towards their T2D. Suggesting that conflating religion and ethnicity can create conflict is decisions for T2D management.

> *Again, I think that's more your religion. I can see why, and I know what it does, and I know how I felt when I used to fast, but I wouldn't tell friends and family that. I wouldn't tell my parents or whatever that I'm more tired than usual. Obviously a fast is a fast. It's supposed to be a test, but if I told them, they would have stopped me from fasting, but I didn't want it. I didn't feel right not fasting* (Interview 5, Lines, 263-267).

> *…now, with the young generation and most of the kids like my kid, you know, coming up, the UK generation, well, they know more about it, you see, because they've been studying in school, and many of them are doctors and all that, you see. Now they say, you see, this oily food is no good, no good for kiddies. Cut it down and that. This is all now going into the temple as well (*Interview 11, Lines 217-221).

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6.5. Discussion

This study aimed to explore factors implicated in diabetes self-management in SA patients from multiple ethnic and religious backgrounds to represent the heterogeneous nature of the SA population. A new GT framework is presented which highlights the complexities that are embedded in the psychological processes that SA patients face when self-managing their T2D. The following analysis presents one core category patient centred care which explains individual’s interpretation of their T2D, how they engage with self-management behaviours and how they prioritise diabetes, within the context of their lives.

For SA patients, living with diabetes has been identified to cause distress and this needs to be taken into account (Sidhu & Tang, 2017). It is noteworthy that although psychological distress is not a new concept as it can lead to a negative emotional impact (Dennick, Sturt & Speight, 2017). Emotions surface in specific situations and emotional distress is a reaction to perceived health threats (Fisher, Gonzalez & Polonsky, 2014). However, in addition to this standard psychological distress, SA patients report additional complexities with communication and understanding. Previous literature has acknowledged how complex T2D communication can be (Linetzky, Jiang, Funnell, Curtis, & Polonsky, 2017). For SA patients an additional layer of communication complexity is present, this manifests in two ways 1) ‘foreign language’ is assumed to be a barrier, and translation becomes a focus of consultations, which impacts on the detail provided, and as such patients believe their consultation has been overly simplified and 2) SA patients do not believe their individual needs, relevant to their culture, religion and/or lifestyle are being met and as such they perceive to have reduced personalised centred care.

The HBM (Rosenstock, 1974) has been used in the context of self-management behaviours. The HBM model entails four constructs; perceived susceptibility, perceived severity, perceived benefits and perceived barriers this readiness stimulates the desired behaviour. The concept of self-efficacy which is one of the latest constructs added to HBM (Rosenstock, 1974), also leads to confidence in the ability to successfully act. The findings from this study partially support the HBM, for understanding diabetes self-management behaviours in SA. For example, this study highlights the notion that patients are more likely to adhere or engage with their T2D management advice and behaviour; if they perceive their T2D to be severe (and not simply a lifestyle conditions) and if the action (T2D self-management advice) was considered beneficial. However, in this study religion and culture beliefs also influence a person's cues to act upon their T2D advice, and this is a new variable which should be considered with the HBM (Rosenstock, 1974) (or other psychological models).

Health professionals evaluate patient’s health literacy during consultations, and as such, they make a judgement how much and what information to provide to the patient. This communication decision may be influenced by other factors (such as limited consultation time (Bos-Touwen, Trappenburg, Van Der Wulp, Schuurmans, & De Wit, 2017). However, participants interpretations of these events were negative; they did not feel T2D had been fully explained. Indeed, patient’s interpretations of self-management behaviours varied. This variation in assessment of a patient’s health literacy, understanding, and ability to engage in self-management behaviours was deemed to influence the patient's engagement negatively and thus reduce adherence to any advice received (Estacio et al., 2015; McDowell & Grant, 2016). Subsequently, a patient’s engagement and acceptance of any health advice offered by the health professional is evaluated from this (negative) perspective (Patel et al., 2014). On-going encounters reinforce these perceptions and in turn may help explain why SA patients do not access or engage in health services in the same way as Caucasian patients (Patel, Phillips-Caesar & Boutin-Foster, 2012).

Current resources and support implore the question ‘is current education communicated or promoted in a way that is meaningful to patients’? It was evident that there was little consistency in offering T2D education, despite NICE guidance (2015) recommending that all patients should be given such an opportunity. It is noteworthy that patients who took the opportunity to receive education reflected on their experiences, and that overall did not perceive the education to ‘meet their needs'. The participants reported it as too generic, not personalised and not tailored to their cultural requirements (Creamer, Attridge, Ramsden, Cannings-John, & Hawthorne, 2015; Hawthorne, Robles, Cannings-John, & Edwards, 2010; O’Hare et al., 2004).

More specifically, patients found it difficult to engage with the advice as they believe they are not receiving personalised patient-centered care, particularly, patients perceived that the information received was not personal and relevant to them, and there was lack of consistency in the advice. This was also highlighted in Patel et al., (2014) study which also found patients would not discuss fasting with their health professional as they felt they would not understand how important it is for them to engage in Ramadan. It is important to understand the patient's psychological perspective and how they perceive their diabetes, as when there is a miss-match, and the advice becomes not meaningful to them. Personalised patient-centered care is detrimental to their reported experience, this influences the patient outcome, and how they cope and manage their condition (McColl-Kennedy, Danaher, Gallan, Orsingher, Lervik-Olsen, & Verma, 2017). Although there is an acknowledgment with regards to communication between the health professional and the patient there is a large emphasis on language, this study highlights that there needs to be focus around 'needs' as this would provide a more patient-centered care which is more specific to the patient (Bellary et al., 2008; O'Hare et al., 2004; Srimanunthipol, Beddow, & Arakaki, 2000).

Psychological and social factors are largely ignored by health professionals (Alhomoud et al., 2013). However, these elements are important especially at diagnosis as these psychological factors influence patient's overall management of diabetes. If patients receive personalised patient-centered care from the outset, this can eliminate the psychological consequences, which can allow patients to understand the condition (Kinmonth, Woodcock, Griffin, Spiegal & Campbell, 1998). It appears currently, where services are doing a little bit of the personalised care model, they are not doing enough as they are really missing the psychological element which can help with personalising the care of the patient.

These findings are broadly in-line with communication theory Watzlawick and Beavin (1967) identified two components of communication: ‘content’ and ‘relationship’. The ‘content’ component represents the message, verbal terms and how the information is communicated. The ‘relationship’ is the people involved in the communication process. In this study, the relationship appears to be focused on the health professional role rather than a partnered care approach with the SA patient. The content of the communication appears to be lost (or misunderstood) because the personalised aspect of care is considered missed. Cultural beliefs, religious needs and ethnic understanding of T2D are not being targeted. This creates conflict in the patient – health professional relationship.

The SRM (Leventhal, Meyer & Nerenz, 1980) is a model that can help understand the patient’s representation of the condition. Integrating this model could highlight the health representations, i.e. diabetes identity could explore psychological beliefs, coping mechanisms could help the health professionals understand how patients are reinforcing diabetes as priority and can highlight adverse effects, i.e. blame other conditions (mental health problems) and this can lead to identifying the outcome they chose which influences the behavioural aspect of diabetes self-management.

The diverse, heterogeneous nature of the SA population means that labelling patients as SA, without considering their ethnic sub-group, religion or cultural identity hides the true extent of diversity across patients (Bhopal, 2002). Within these different groups of patients, there are cultural differences and similarities which have been identified to influence diabetes self-care such as, causing social offence (Lawton et al., 2008), and religious influences, such as fatalistic beliefs about diabetes (Lundberg & Thrakul, 2013).

Based on this study ethnicity and religion may influence self-management in different ways. For example, if a GP advised two SA's, from Indian descent, about fasting, even though they may have the same ethnic background they may still respond differently to that same advice: e.g. if one is Muslim and one in Hindu, advice not to fast may be more problematic for a Muslim, compared to a Hindu (Almalki & Alshahrani, 2016; Jaleel, Raza, Fathima & Jaleel, 2011; Lee, So, Yok-Shiu, 2017). Similarly, two SA patients, from Indian descent, may respond in different ways to dietary guidelines issued by a DSN due to their religious differences. For example, practising Muslims follow a halal diet compared to practising Hindus who follow a vegetarian diet. Therefore some dietary advice given by health professionals may conflict with their religion (Agrawal, Millett, Dhillon, Subramanian & Ebrahim, 2014; Shridhar et al., 2014).

Previous evidence exploring SA patients (Lawton et al., 2006; Macaden & Clarke, 2006; Mutuota et al., 2017) has made no mention of religious nuances. Overall, these studies highlight the importance of cultural factors in self-management but conflate ethnicity and religion. These two domains are relevant in different ways as some ethnic and religious distinctions fall under the ‘South Asian' umbrella, which may differentially influence diabetes self-management. For example, British Muslims are often viewed as a single community, despite being ethnically heterogeneous (Peach, 2006). It is important to distinguish ethnicity from religion as the impact of religion may be moderated by cultural dimensions, which influence health care for Muslims. There has been a number of studies that have looked at diabetes and fasting (Patel et al., 2014), but none have addressed the intrareligious issues that influence health beliefs.

6.5.1. Future research

Further studies are required to identify what might be practically useful for patients, (e.g. to improve communication and self-management behaviours). It is important for health providers to have a better understanding of ethnic and religious differences within the SA community. While this current study provided insight into patient’s perspectives, patients did acknowledge the influence of friends and family on their T2D behavioural decisions. Thus, future research should consider how family and friends also influence patient behaviours.

6.5.2. Strengths and Limitations

This study has further enhanced the evidence base by presenting a theoretical model to describe the underlying psychological applications relevant to diabetes management. While undertaking this study, the researcher encountered some limitations with regards to recruiting participant’s which took longer than anticipated, (as recruitment was through health professionals, they reported that some patients preferred to be interviewed by someone they knew personally). However, data saturation was achieved to allow a comprehensive analysis of the study. One aspect that was taken into account was researcher bias. As the researcher was from an SA background, it was essential to be aware of and vigilant of researcher bias, this was achieved by having regular supervision to mitigate any bias, and to ensure valid findings.

6.5.3. Conclusion

This qualitative research has provided insight into factors implicated in diabetes self-management in SA patients from multiple ethnic and religious backgrounds. Patients did not believe that they had received personalised and individual patient care. They perceived that the health professionals did not recognise their identity, specific SA social-cultural identity, religious needs or cultural, behavioural influences. Therefore, patients did not believe their self-management advice had addressed their personal health beliefs, relevant to their SA lifestyle and as such these beliefs impacts their decision to implement T2D advice received from health professionals.

6.5.4. Key points from this study

- Lack of patient-centred care contributed to patients lack of engagement and implementation with advice provided by their health professional (which in turn encouraged them to seek advice and feedback from others within their social network, e.g. layperson, family members or religious leaders to help make appropriate decisions).
- Cultural and religious nuances regarding lifestyle behaviours were highlighted across the heterogeneous nature of the SA population groups. Consequently, because patient’s individual social-cultural, religious and ethnic differences were not acknowledged by their health professional, patients did not believe that the self-management advice

(such as dietary advice) fitted their needs and this created dissonance from the health professionals and T2D services.

Chapter 7: Study 3- A qualitative study exploring the experience, attitudes and views of family members involved in the care of SA people with T2D.

Study 3 - Chapter overview

Previous research has highlighted that people with T2D have better self-management when they have social support. As highlighted in earlier chapters (Chapters 3, 5, & 6) within the SA population, cultural and religious traditions influence diabetes self-management. However, limited research has explored the role of family members in providing social support to help manage their T2D. The present study aimed to address this gap in the literature, by exploring the experience, attitudes and views of family members or friends involved in the care of SA individuals with T2D.

Seven semi-structured interviews with family or friends involved in the care of SA individuals with T2D were conducted in the North West of England (Bolton, Preston, or Blackburn). A GT method and analytical approach was adopted (Strauss & Corbin, 1990). Data collection and analysis occurred simultaneously.

Two core categories emerged: 1) family roles, which highlighted that different family members adopt different types of supporting roles, and 2) diabetes seriousness and acceptance, which referred to the fact that these family members accepted diabetes as a normal part of life, which in turn limited their role in offering ongoing active support

In conclusion, family members influence diabetes self-management in significant others, the support they offered varied depending on who they were (e.g. wife, daughter, brother) and how much they accepted diabetes as part of a normal life.

7.1. Introduction

The previous PhD chapters have explored T2D self-management behaviours from both health professionals’ perspectives and from patients with T2D themselves. However, T2D is a chronic disease that affects not just those with the diagnosis of T2D but entire families. Both the individual with T2D and their family members (e.g. spouses, offspring, and close friends) may benefit from gaining knowledge about T2D.

7.1.1. Literature review

7.1.1.1. T2D and social support

There is documented evidence which suggests that social support can help people engage with T2D self-management behaviours and subsequently enhances clinical outcomes (Carolan, Holman, & Ferrari, 2015; Koetsenruijter, van Eikelenboom, van Lieshout, Vassilev, Lionis, Todorova,et al., 2016; Strom & Egede, 2012; Vassilev, Rogers, Sanders, Kennedy, Blickem, & Protheroe, et al., 2011).

Previous research with people living with T2D has explored their experiences (Lawton et al., 2006; 2008; Mayberry & Osborn, 2012; Majeed-Ariss et al., 2015), and within these findings, social support from family and friends has been identified as a positive factor to enhance self-management behaviours. According to van Dam, van der Horst, Knoops, Ryckman, Crebolder, and van den Borne (2005) social support comprises of emotional, appraisal, informational and tangible assistance. A basic definition of social support is as follows: 'an exchange of resources between at least two persons aimed at increasing the well-being of the receiver' (Shumaker &

Brownell, 1984 p.11). An example of social support in diabetes management could be altering routines to fit diabetes self-management needs (Kadirvelu, Sadasivan & Ng, 2012). More specifically, family support towards diabetes management can have a positive impact on overall diabetes clinical outcomes and management (Macaden, & Clarke, 2015).

A recent qualitative study conducted by Grabowski, Andersen, Varming, Ommundsen and Willaing (2017), explored difficulties family members faced when supporting another with T2D. The results identified six areas that were challenging for the family members: knowledge, communication, support, everyday life, roles and worries. Radical hermeneutics (Rasmussen, 2004) analysis suggested that the connection between family health identity (i.e. how individuals observe and respond to their health) and healthcare authenticity (i.e. genuine care) can potentially influence and, if seen as a positive aspect, help reduce the difficulties family members face with regards to the six areas.

A systematic review (Pamungkas, Chamroonsawasdi & Vatanasomboon, 2017) explored effective self-management methods offered to family members to help people with poor blood glucose control. The review concluded that a model of family engagement could help people with diabetes manage better and improve clinical outcomes. For example, an included article within this review, Aikens, Rosland and Piettewe, (2016), developed a mobile health service offering pre-recorded self-management support messages tailored to individuals focussing on their health status and self-care. Informal caregivers were also invited to get involved, who could receive recommendations to support the person with diabetes. 39% of the participants opted to involve informal caregivers. The results indicated that the combination of the mobile health service and the involvement of informal caregivers improved aspects of diabetes management, e.g. medication adherence and psychological distress. Tabasi, Madarshahian, Nikoo, Hassanabadi and Mahmoudirad (2014) suggested that teaching family members specific techniques (provide information about effective roles) could help the family member providing a more supportive role to the person with T2D.

Family relationships can provide an important source of support for a person with T2D (Baig, Benitez, Quinn, & Burnet, 2015). However, previous research has suggested that family members may perceive diabetes as a more severe illness than those people with diabetes themselves (White, Smith, & O'dowd, 2007). They may be continuously concerned for the health of the person with diabetes (Rosa, Sunvission, & Ahlstrom, 2007) and may have fears and worries about the illness. Fisher, Chesla, Skaff, Mullan and Kantar, (2002) found that partners (especially female partners) experienced high levels of psychological distress themselves. Which may in itself suggest how T2D can cause additional negative (health) outcomes to others without T2D and in turn of a family member is also distressed this could have an additional negative impact on the person with T2D (directly impacting on their T2D self-management behaviours and clinical outcomes, or indirectly by impacting on their T2D general wellbeing and relationships). This is, however, a very understudied research topic and little is known about family members T2D distress (Kovacs Burns, Nicolucci, Holt, Willaing, Hermanns, Kalra, et al., 2013).

NICE clinical guidelines (NICE, 2015; 2017) acknowledge the roles of family members and recommend that structured education is offered ‘to adults with T2D and/or their family members or carers (as appropriate)’ (NICE 2015, p.9). However, the focus of most diabetes interventions involves only people with T2D and do not typically include family members for support (Norris, Engelgau & Narayan, 2001). A small number of interventions have included family members in T2D care. However, the limited evidence has created difficulty in identifying effective interventions involving family members (Spencer-Bonilla, Quiñones, & Montori, 2017; Torenholt, Schwennesen & Willaing, 2014).

A randomised control trial (Kang, Chang, Chen, Liu, Liu, Chang, et al., 2010) compared family partnership intervention care with standard care across six outcome measure (1) haemoglobin A1C, (2) BMI, (3) lipid profile, (4) family supportive behaviours, (5), knowledge of and attitudes toward diabetes, and (6) diabetes self-care behaviours. Out of the 6 outcome measures, there were no significant differences in 4 (1) haemoglobin A1C, (2) BMI, (3) lipid profile and (6) diabetes self-care behaviours 6 months post-intervention. However, there were significant differences in family supportive behaviours and patients' knowledge of and attitudes toward diabetes between the groups. This suggests that involving family support can positively influence diabetes self-management.

Notably, Gilliland and colleagues (2002) trial compared a three-arm intervention a 1) psychoeducational group involving people with diabetes and their family; 2) an individual psychoeducational session without family, and 3) a control group (usual medical care). Overall, the study reported a slight increase in glycemic control in the intervention (psychoeducational group involving people with diabetes and their family) compared to the control group. Suggesting that the involvement of family members in diabetes can have a positive impact on patients' clinical outcomes (Martire, 2005).

Myers, Fernandes, Arduser, Hopper and Koehly (2015) conducted a qualitative study in the USA with first-degree relatives of individuals with T2D, 33 interviewees from 22 families were recruited, of which the majority were Caucasian women. Myers and colleagues reported 3 categories: reactions to T2D, perceptions about T2D cause and familial risk, and communication about T2D. They discuss these findings in relation to relative's reactions and perceived cause, which shaped their attitudes and beliefs consequently influencing their communication patterns.

7.1.1.2. SA social support and family dynamics

Despite the evidence to highlight the important role of social support in T2d management, there has been very little research which had explored relationships and social support across and within ethnic variants of population groups. Social support is particularly relevant for individuals from a SA population (Venkataraman, Kannan, Kalra, Gambhir, Sharma, Sundaram, et al., 2012). A qualitative study by Stone, Pound, Pancholi, Farooqi and Khunti (2005) interviewed people with T2D of whom 75% of participants were SA. They reported that family members provided emotional and practical support, and this was particularly pertinent to those individuals who were SA, compared to participants who were white Caucasian.

7.1.1.3. SA family dynamics

It is essential to understand the SA family dynamics. SA people in the UK do not live in a traditional nuclear family (Ballard, 1982). SA families are very complicated, and centre around an extended family system. SA families may have immediate family plus grandparents and cousins often living under the one roof (Lau, 2000).

Indeed, the literature has highlighted the positive effects of social support. However, it is noteworthy, that SA people with T2D face additional challenges such as feeling guilty or criticised by family members (Kadirvelu, & Sivalal Sadasivan, 2012). More specifically, SA people with T2D have reported that they (often) do not control what they eat as they are not the ones who cook (Lawton et al., 2008) and this can lead to poor diabetes outcomes (Ansari, Hosseinzadeh, & Zwar, 2016). SA population have lifestyle commitments such as festivals and religious obligations (e.g. fasting) where people with diabetes encounter numerous difficulties, failure to engage in such activities may impose shame or offence creating a need to part take (Macaden & Clarke, 2015; Singh et al., 2012).

Overall, there is a lack of evidence exploring family members' experiences and perspectives of their role in providing social support to individuals with T2D, especially from a SA background. Capturing these perspectives could identify how social support should be implemented and understand the needs of SA individuals with T2D. Adding family member’s perspectives to the GT research could enhance understanding the needs of the SA population further, and hence may offer additional insight into the delivery of T2D care. By taking the family members’ perspective, this can find the best way to support family members in their important and challenging role; it is vital to know how they are involved with and support their family member with T2D and to consider how they may influence a person with T2D self-management behaviours.

7.1.2. Aim

The aim of this study was to explore the experience, attitudes and views of family members (e.g., spouses, family, and offspring) of individuals with T2D, and to consider how family members influence a SA persons self-management behaviour.

7.2. Methods

7.2.1. Design

The study adopted a qualitative approach using an exploratory design where in-depth interviews were conducted to explore the experience, attitudes and views of a family member or friends involved in the care of SA patients with T2D. The present study used GT analysis (Strauss & Corbin, 1990) to derive a framework from data saturation (Glaser, 1978) highlighting key issues. This study was informed and directed from the findings of Study 2, from those individuals with T2D (*Chapter 6*).

7.2.2. Sampling

Whilst carrying out study 2 (*Chapter 7*) all the participants (with T2D) were invited to provide details of a family member involved closely in their care or management of their T2D. Recruitment of participants commenced until perceived data saturation (Glaser & Strauss, 1971) had been reached (See analytical procedure). The analytical procedure followed a similar pattern to the previous qualitative studies (*Chapters 5, 6*).

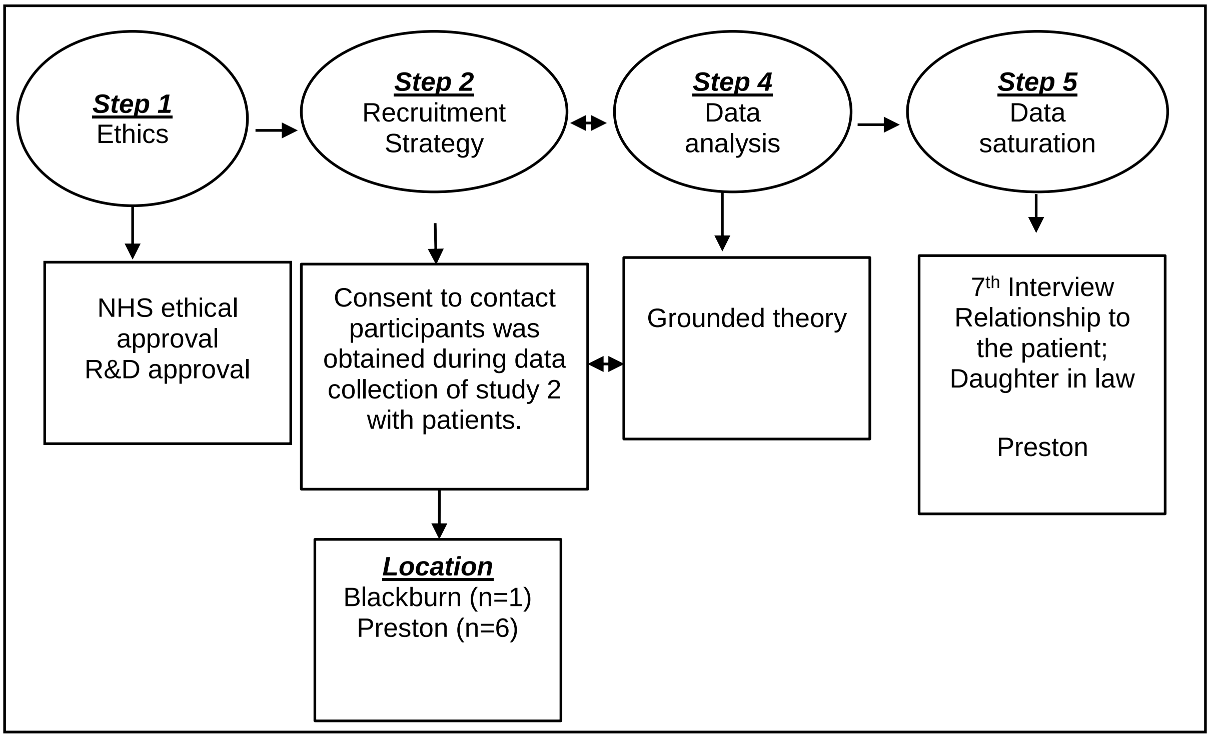

Figure 7.1: Overview of study methodology

Participant inclusion criteria:

The study aimed to include the family members of people with T2D. Purposeful sampling was conducted as directed by participants in study 2 (*Chapter 6*). It is noteworthy that not all participants in study 2 (*Chapter 6*) nominated a family member for recruitment into this study (hence participant recruitment was limited by this factor).

Overview of participants

Semi-structured interviews were conducted with seven family members. Six females and one male with a mean age of 41 years (range 20-61 years). Six of the participants were Indian, and one was African (*See Table 7.1* for characteristics of participants). All interviews were conducted at the participant's homes.

Table 7.1: Characteristics of Participants

	Name (pseud-onym)	**Recruited from study 2 participant**	**Relationship to patient**	**Age**	**Gender**	**Ethnicity**	**Religion**	**Job title**	**Area**
1	Najma	P7, Male, Aged 47, T2D duration 12-13 years	Wife	44	Female	Indian	Muslim	Employed	Preston
2	Zaina	P10, Male, Aged 56, T2D duration 1 7 years	Wife	61	Female	Indian	Muslim	Homemaker	Preston
3	Neelam	P13, Male, Aged 61, T2D duration 9 years	Wife	55	Female	Indian	Hindu	Homemaker	Preston
4	Isla	P8, Female, Aged 46, T2D duration 3 years	Daughter	20	Female	Indian	Muslim	Employed	Preston
5	Naila	P17, Female, Aged 43, T2D duration 6 years	Daughter	30	Female	African	Muslim	Employed	Blackburn
6	Rikesh	P6, Male, Aged 60, T2D duration 14 years	Brother	55	Male	Indian	Jahowas Witness	Self-employed	Preston
7	Aisha	P9, Female, Aged 54, T2D duration 8-9 years	Daughter in-law	25	Female	Indian	Muslim	Homemaker	Preston

7.2.3. Materials

A semi-structured interview schedule (*Appendix 7.1*) was informed by the topics and issues identified from existing literature and analysis of previous studies (*Chapters 2, 3 & 6*). The key topics for the interview schedule explored: what diabetes self-management meant to them as individuals and for their family member with T2d; and their experience of adherence, information and struggles (*Table 7.2*). Interviews included open-ended questions to allow participants the opportunity to explain their experiences fully. The digitally recorded interviewers were transcribed verbatim (by TP), and transcripts were stored on the password-protected university server.

Table 7.2: Interview Schedule

Key Topics
1. What does self-management mean to you?
2. What are your experiences of adherence to the self-management regimes? a. Diet b. Exercise c. Medication d. Self-monitoring of blood glucose
3. What are your experiences of the information available about self-management?
4. What are your experiences of the struggles your family/friend have and find difficult about self-management?

7.2.4. Procedure

Before holding the face-to-face in-depth interviews, the researcher contacted the participant to provide more detail about the study. Data was collected using in-depth face-to-face interviews. Four interviews were conducted in English and three were completed in Gujarati, taking a mean duration of 18 minutes. The audio recordings of the Gujarati interviews were translated into English at the time of transcribing by the researcher, following the same process as described in Study 2 (*Chapter 7*). Interviews were conducted between September 2015 to February 2016.

A PIS (*Appendix 7.2*) was available in the participants preferred language (e.g. available in English, Gujarati or Urdu), this sheet explained the purpose of the study and what it involved, the participant had the chance to ask any questions or queries, once that was completed a consent form (*Appendix 7.3*) was signed by the participant and researcher. Participants were advised that taking part in the interview was voluntary, so they did not need to answer any questions that they did not want to and could have ended the interview at any time. The participant filled out a demographic screening form (*Appendix 7.4*) which had information on their age, nationality, religion, length of diagnosis and employment status. Privacy was ensured as the interviews were conducted in a private environment in the participants' home. Anonymity was discussed as the participants were advised that quotes could be published, and any personal names would be replaced with pseudonyms. Once the interview was complete, the researcher switched off the recorder and thanked the participant for taking part and asked if they had any questions. A debrief (*Appendix 7.5*) was available to read at the end of the interview.

7.2.5. Reliability and Validity

Four interviews were conducted in English and three were completed in Gujarati. Audio recordings were transcribed verbatim by the researcher. For quality checking (Fujii, 2017; Temple & Edwards, 2002; Temple & Young, 2004), the same process was followed as described in Study 2 (*Chapter 6 pages 190*). (*See Chapter 4, page 133 – sub section 4.8 further information on this process*).

7.3. Analytical Procedure

Data analysis as described in Chapter 4 was completed for this study. The analysis was primarily conducted by the lead researcher, with coding process ratification and discussions occurring between the researcher and DoS.

This study was limited by sampling referral as directed from participants in study 2 (*Chapter 6*). It was recognised that this study did not reach theoretical saturation (Strauss & Corbin, 1998), the research team agreed that the study did, however, appear to reach data saturation (Glaser & Strauss, 1971) (at participant 7), and given no new ideas were being raised from participants (Glaser & Strauss, 1971). In this study, 544 open codes (*Appendix 7.6*) were subsequently grouped into 21 axial codes (*Appendix 7.7*) with various supporting memos (*Appendix 7.8*). Selective coding, refinement and review supported the development of a GT framework consisting of two core categories, which formed the basis of this theoretical framework (*Figure 7.2*).

7.4. Analysis

The participant’s data was analysed into two core categories 1) *Family roles* and 2) *Diabetes seriousness and acceptance*. These categories interact to inform how family members perceived and offered support to their family member with T2D.

7.4.1. GT framework:

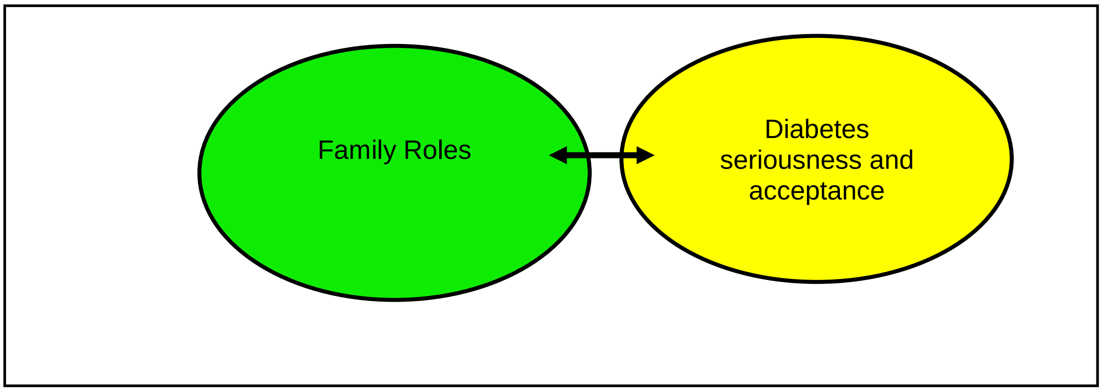

Figure 7.2: Roles, seriousness and acceptance model

Core category: Family Roles

This category explored the types of family support offered, specifically comparing emotional vs practical support. It also explored specific family roles and their impact on T2D management overall. The participants who were wives of individuals with T2D reported trying to be ‘proactive' supporting their husbands to manage T2D effectively. They reported both feeling empathy and guilt:

> *Yes, support is important, you know when its husband and wife, if ones not around then it is hard. With support, it gets better. If I would have known from the beginning, then I wouldn't have let diabetes go so high.*
> (Interview 1, Wife, Lines 165-166, 168)

> *Well, if the other want to eat something with more masala (spices) then I make something light for him and not so strong, that’s the way we do it. When I make something sweet then I give him a little bit only. When those guys are eating it they tell him he shouldn’t eat it, but if am not there, like if I have gone upstairs, he gets tempted so he eats a little obviously that happens.*
> (Interview 2, Wife, Lines 40-44)

The role of other family members (e.g. daughters, brothers and daughters-in-law) offered less emotional support but was described in terms that were more practical. These family members appeared to be more health literate and have a broader understanding of health generally than the person with T2D. However, whilst offering some practical support to the person with T2D, they also expressed a lack of understanding of T2D. They did not typically perceive their role to influence the behaviours of the person with T2D but just to be aware and accepting of their condition.

> *Just reminders and encouragement kind of thing, yes. Sometimes you have to be a bit more direct. It's difficult always to take advice in a normal day-to-day life.*

> *People do that sometimes, people resist that, particularly when a person has other issues. You've got to be very sensitive and delicate as to how things are put when you say something or not.* (Interview 6, Brother, Lines, 81-84)

> *I just say that you can't have any more. That's it. I won't be, "Oh, you can't have any", from having it, that you can't have any.* (Interview 4, Daughter, Lines, 132-133)

Family members (mainly spouses) reported seeking information about T2D in an attempt to be supportive. However, they were uncertain about what ‘support’ they should offer. Overall, family members did not receive guidance or information about how to be supportive. They referred to information offered to them via healthcare service as ‘ad-hoc’. Family members reflected on the balance between being encouraging against ‘nagging’.

> *It could actually, yes, because I think obviously this condition, because if he's like told, if you will, to do something, then he'd probably do it, whereas if I say it, it's like nagging, and that's in that in different things, with other things. So I suppose if he was told, "You must exercise", then he may take that more of an instruction from others than he would from me.*
> (Interview 6, Brother, Lines, 132-135)

> *He likes to eat at night, the nurse made him stop eating crisp and chocolate, I tell him a lot, but he doesn't listen to me, I told her to explain and tell him to stop, he's stopped eating crisp and chocolate at night, we used to go see couple times but that stopped so he started again in the middle, he started eating crisp and chocolate, that's the problem. Sometimes he's really good and controls and sometimes when he gets tempted, hel say 'you die once' so just eat it, that's what he does, that where the problem is, but when he takes proper control, alhumdulilah it's really good. He can't do much of other exercises, the gym exercises he can't do much of because his legs hurt, that why, but he walks*
> (Interview 2, Wife, Lines, 124-131)

Although spouses were able to acknowledge that (especially in relation to eating behaviour) peer support was essential to help maintain an appropriate diet. They emphasised contributing factors, such as cultural roles that are common in SA population. For example, cultural norms within the family dynamics were still broadly referred to: that men were the breadwinners and females were the homemakers. For these families, such roles created additional challenges within T2D management. Especially for men, who in these instances had no control over meals and cooking methods (as this was the women's role), this is an issue also recognised in previous research (Bhopal et al., 2014; Lawton et al., 2008; Lucas et al., 2013). Subsequently, men with T2D often reported a sense of diminished responsibility (Gucciardi, Wang, DeMelo, Amaral, & Stewart, 2008) especially regarding behaviours linked to the dietary and cooking behaviours.

> *Well, if the other want to eat something with more masala (spices) then I make something light for him and not so strong, that's the way we do it. When I make something sweet, then I give him a little bit only. When those guys are eating it, they tell him he shouldn't eat it, but if am not there, like if I have gone upstairs, he gets tempted so he eats a little obviously that happens.* (Interview 2, Wife, Lines, 40-44)

> *I think, because our Indian food is quite rich and heavy, oils and stuff like that, and salt and stuff like that, I think that's a challenge in itself, but when she does cook, she tends to put less salt and less oil in, so we're all used to eating like that anyway.* (Interview 7, Daughter in-law, Lines, 42-44)

> *Yes, on Eid he eats everything, you can't stop him on Eid, he just eats everything, even if I try to stop him his mum lives in front so he will go there and eat, so he just eats it, and then he will say my sugar is high so I will have to more insulin.* (Interview 2, Wife, Lines, 82-84)

Family members accepted the role of the ‘woman as cook' and trusted she was responsible for adapting food and making mealtimes ‘healthier'. Beyond this, there was limited consideration of how family members could offer emotional or practical support regarding dietary intake appropriate for someone with T2D.

> *I think, because our Indian food is quite rich and heavy, oils and stuff like that, and salt and stuff like that, I think that's a challenge in itself, but when she does cook, she tends to put less salt and less oil in, so we're all used to eating like that anyway.* (Interview 7, Daughter in-law, Lines 42-44).

Core category: Diabetes susceptibility and acceptance

Family members were uncertain of the severity of T2D. Their understanding and knowledge about T2D was limited. T2D was reported as ‘normal’, ‘accepted’ and in some instances an ‘inevitable’ condition. The concept of living with T2D was part of life and considered ‘a social norm’ within the SA community.

> *Not really, no. I mean, I don't know how levels of seriousness you sort of put in diabetes, but I don't think he's in a very serious condition, as it were, and I think if he were to get motivated to the other things, then he could work through it, and not get worse.* (Interview 6, Brother, Lines, 125-127)

> *I'm not too sure, because with her, her sisters and that have got it as well, so it's more in the family. So maybe*

> *that's probably what sort of made her change.*
>
> (Interview 7, Daughter in-law, Lines, 102-103)

Moreover, family members compared the diagnosis of T2D to other health conditions, which were perceived to be more serious. For example, heart disease was deemed more important and life-threatening. Mental health issues were also described as more problematic and required more family intervention and support than for someone with T2D.

> *if it was like putting it on a scale, her diabetes would probably be a nine, and her other condition would be a ten, because that's more of a condition than it is for diabetes, because obviously that's all diet-controlled or whatever, and you have medication for it and stuff, but the other one is your pain and blah blah blah.* (Interview 4, Daughter, 101-104)

> *Yes, he has other conditions, and when he's ill, he's not really aware, so he needs help, he has mental health problems and depression and sometimes it's really bad. That day he was so normal, and when there is a problem in his medication he becomes really unwell, and he's not aware, and that’s what happens.* (Interview 2, Wife, Lines, 46-49)

> *And he's self-managing that without medication, which he can do. It's complicated because of his mental health issues, that it's all related to that, that I think*

> *sometimes the more things he has, that seems to be...It's difficult to describe it really, that with not having a lot of other things to think about, in a sense, to do, he will focus more intensely on any illnesses or things that he has kind of thing.* (Interview 6, Brother, Lines, 58-62)

None of the family members reported being offered specific advice or guidance on how to support a member of their family with T2D. Whilst a few reported attending clinical appointments alongside the person with T2D (as routine rather than specifically invited), these were not directed towards the family members themselves.

> *I don't know obviously exactly what help she gets from the nurse and stuff, because I'm at work most of the time, but she does get some sort of help, and I know she did go to get some courses and stuff to learn about how much sugar she has, what certain foods have so much sugar and blah blah blah. She was going to some courses and things like that, so obviously, that helped her to understand what foods had hidden sugars and stuff in foods and drinks, and things like that.* (Interview 4, Daughter, Lines, 136-141)

> *Or that's been readily available at doctor's surgeries or anywhere else. Any information that I did have access to was via the Slimming World group and the Slimming World books, and obviously, it ticks it off as one of the*

> *things as well with regards to reducing the risks of diabetes, and weight loss reduces the risk of developing type two diabetes. And it's a known fact. But yes, I've not had any access to any information of that sort.* (Interview 5, Daughter, Lines, 194-198)

Family members understanding, acceptance and beliefs regarding the severity of T2D varied. Their beliefs were mainly informed by community values and layperson perspectives. Therefore, family members have a lack of knowledge, perhaps misconceptions, unclear about their roles in supporting the person with T2D and consequently could lead to them not understanding how these factors could impact on diabetes self-management behaviours and as such lead to guilt and frustration from the family member.

> *Yes, in the starting, then you don’t have much experience, yeah she's right, at that time there was no DESMOND course, you just use to get a leaflet from the nurse from the Doctors place, in the beginning I just got a leaflet and a book, a machine to check, this was in the beginning and then slowly, with time I started getting experienced that’s how was it...* (Interview 2, Wife, Lines, 213-216)

> *If I would have known from the beginning, then I wouldn’t have let the diabetes go so high.* (Interview 1, Wife, Line 168)

> *Household, like in the house, obviously with things that we eat, because obviously there's more young people around the house, so we eat more sugary foods all the time, and obviously day in, day out, that's probably what's most challenging for Mum, to what she feels and stuff, based on what we eat.* (Interview 4, Daughter, Lines 23-26)

Despite this, younger family members (e.g. daughters, daughter-in-law) were able to acknowledge the role of healthy lifestyles as a general concept in the management of T2D. They were more aware of healthy eating, and the benefits of regular intense PA. However, at times, they described avoidance strategies, such as not to have to change their (family) lifestyles (especially SA foods and cooking methods) because of someone else's T2D.

> *We all cook like similar anyway. My sister-in-law cooks, we all cook similar. We all use like the healthy oils and things like that, so it's like subconsciously. I won't think, "Oh, I'm going to put this oil", because I do automatically anyway.* (Interview 4, Daughter, Lines 188-190)

> *We all eat the same, so when we're like frying onions, we'll put less oil in, less salt in as well. Yes.* (Interview 7, Daughter in-law, Lines 46-47)

> *Yes. When I make stuff, I'll make enough. So I tend to make like tandoori roast chicken, and I've made that Slimming World style, and they'll all happily eat that. And I'm not using loads of...You know when you get yoghurt, and it's full fat, I don't use that, I'll use something else, or make adjustments to it, and they'll happily eat it.* (Interview 6, Brother, Lines 98-101)

7.5. Discussion

This study offers insight into the experience, attitudes and views of a family member involved in the care of SA patients with T2D. The two core categories (Family roles and, Diabetes seriousness and acceptance) suggest that the influence of family members is complex and depends on who these individuals are. The quality of care may vary depending on who is giving the care (e.g. wife, daughter, brother). The support can vary in terms of emotional and practical which can influence diabetes management. Diabetes seriousness and acceptance may echo previous studies in SA community where diabetes is seen as a norm (normal everyday condition). For example, Lucas, Murray, and Kinra’s (2013) review reported that diabetes was considered to be common in SA communities. Therefore SA individuals felt T2D was not something they needed to worry about (because as a common condition, most people appear to cope with it fine). Therefore, when T2D is accepted as a diagnosed condition, it may mislead family members into providing only ad hoc support and not acknowledging the on-going challenges the person with diabetes may be facing.

Congruent with the scarcity of previous research exploring family members (Carolan, Holman, & Ferrari, 2015; Vassilev et al., 2011), this study highlights that family members can influence T2D management. To date family members experiences have been largely overlooked particularly in research with SA populations. In this study, wives, of those with T2D, embraced an authoritative householder role: responsible for the family cooking and played an active role in providing both practical and emotional care for their spouse. For women with T2D, husbands reported less practical involvement in their wives T2D management and perhaps a sense of diminished responsibility (Nielsen, de Fine, Gannik, Hindsberger & Hollnagel, 2006). SA women (householders) may therefore not receive as much social support to manage their T2D and hence may be more vulnerable to poorer clinical outcomes. Other family members (e.g. daughters, daughters-in-law, brothers), presented greater overall health literacy, than ‘older' family members (wives, husbands). These younger individuals (often still in education or had completed more education than their family member with T2D) were mindful of living active lifestyles and understood the value of a healthy diet which suggests if encouraged they could help and support their family member with understanding and managing their diabetes. However, the practical application of this support was limited and possibly a missed opportunity. Moreover, the concept of applying this advice as a specific T2D preventative strategy, in their own future health with T2D themselves was not recognised.

Myers and colleagues (2015) presented three categories to explain family members understanding of social support (reactions to T2D, perceptions about T2D cause and familial risk, and communication about T2D). Whilst Myers and colleagues' study was not conducted with the SA population; the findings are relevant here. This current study extends Myers at al's findings further, presenting a psychological understanding of the family member's perspective. Specifically, it was found that when discussing T2D, family members presented acceptance of T2D as part of their community, but also avoided personalising this condition, to themselves or their family members with T2D. They reported a diminished responsibility towards supporting the family member with T2D. This is particularly important to note for SA women who act as the home keepers within a family and may receive less social support from outside the family due to the nature of their family role. As such it may be pertinent to focus on the role and needs of social support for this sub-group of people with T2D.

Of relevance to explaining the beliefs and experiences of family members is the SRM (specifically health beliefs- identity and severity) (Leventhal, Meyer & Nerenz, 1980). The way family members perceived T2D, related to how they defined and identified T2D as part of their community, as an 'inevitable' condition. This also overlaps with Social Norm Theory (Perkins and Berkowitz, 1986), which emphasizes the influence of others and the role it plays in decision-making. With reference to this theory, a persons perceived norms (what we believe to be normal rather the actual normal) are not aligned. In this instance, the misperception that family members have about the seriousness of T2D is not representative of the actual condition. Moreover, family member’s perceptions regarding the consequences of T2D are underestimated. Thus, the role of social support from family members is reduced (and their perceptions may even have a negative impact on a person with T2D self-management behaviours). Both emotional and practical support offered to family members to manage their T2D, is not permitted or utilized as it could be. In addition, family members made social comparisons (upwards and downwards comparisons (Festinger, 1954) to compare their family member to others within the community (with T2D who may be managing their T2D successfully or unsuccessfully; who may not have made substantial lifestyle changes) and comparison to other more serious health conditions (such as comparing T2D to more ‘serious’ and ‘needy’ conditions such as heart disease, or mental ill-health. Despite having access to a wide social network, this lack of inconsistency for social support is particularly problematic for SA population, as the SA family dynamics of living together and the social support they receive might not be helpful, and at worse possibly detrimental as this study supports Mayberry & Osborn, (2014) that family can tempt patients into eating unhealthy foods.

Although NICE, (2015; 2017) suggests that family members and carers should be offered education with patients. This study emphasises that not only do family members report not being offered education; they do not feel actively involved. This has implications for NHS services which should consider how they invite and involve family members in people with T2D care (where appropriate). Moreover, recent statistics report low attendance figures on the T2D structured education programmes (NHS Digital, 2017). This indicates that people with T2D are not attending, and perhaps could be influenced to attend by significant others, such as family members who could offer social support and encouragement. In addition, it would be helpful to consider what information would be useful to family members, and how this is presented or made available to them, as current guidelines do not consider such needs or make explicit recommendations on what social support should involve. Ultimately, more resources and more support are required for family members and friends.

7.5.1. Future research

This study highlighted that family members could play a supporting role in people with diabetes management. Further research is needed to understand the practicalities of how family members can actually support people with T2D and in what ways can they influence attendance at clinical appointments (such as education programmes) and how they can offer emotionally and practical support at home. Despite clinical guidelines such as NICE recommending involvement of family members in the treatment of T2D. Further research to explore what education is needed and how best to deliver key information to family members is needed.

This study focused on the role of social support for those with T2D, although it did not focus on family members own psychological wellbeing. Previous research (Fisher et al., 2002) has suggested that family members may also experience diabetes distress or other mental wellbeing issues as a result of living with a person with T2D, and this may be an area for future research.

Finally, this study highlighted that there might be differences in support type and roles adopted, which again should be considered in the way we expect or promote significant others to offer support.

7.5.2. Strengths and Limitations

This exploratory study utilised GT methodology (Strauss & Corbin, 1990). The participant recruitment into this study was restricted and limited to the referral of participants directly from study 2 (*Chapter 6*). It could be suggested that in study 2 (*Chapter 6*) male participants were more likely to refer their wives, and female participants were more likely to refer their daughters/daughter-in-law's as significant others for recruitment into this study, as they may have perceived these individuals to have more of a caring and supportive role. The recruitment strategy for this study was therefore restricted to study 2 (*Chapter 6*) participant referrals, recommending appropriate family members. Male participants were less likely to be put forward to participate in this study. Females in study 2 (*Chapter 6*) may not have recommended male family members as they were most likely to be perceived as having a limited care role (which may, in fact, highlight the lack of social support available for female SA individuals with T2D).

The researcher acknowledges that the testing of the GT theory itself did not reach theoretical saturation. However, it was deemed that data saturation (Glaser & Strauss, 1971) was achieved given the participants were expressing similar views and experiences. Although a noteworthy explanation for this may be that the sample was limited by the recruitment through study 2 (*Chapter 6*) participants and focused on recruiting female participants to talk about social support (only one male participant). Whilst the participant sample for this study may have been expanded further to include extended family members (and more male participants), it is possible that a reason for the low (ish) participant numbers and focus on female participant referrals is indicative of an overall lack of social support from family members, or indeed highlights a biased assumption that social support is part of a females role.

7.5.3. Summary

This study provided insight into the experiences of family members who supported people with T2D. The findings suggest that family members have an influence on diabetes management. The role and resource of family members in supporting T2D management appears to be underutilised. There is a need to integrate family members into care pathways so that they have an understanding of T2D and how they can help the person with T2D to ensure a positive diabetes self-management experience.

7.5.4. Key points from this study

- Family members play an important role in influencing patient's diabetes self-management. This study highlighted that: wives provided emotional and behavioural support and children/siblings offered practical advice. Female patients may be more vulnerable to having a lack of social support (especially from their husbands, due to traditional roles).

- Family members are important influences in how a patient manages their T2D, and they may have a positive or negative impact on behaviour.
- There is a lack of resources and information available for family members to help them understand diabetes. This encourages the family to make behavioural choices that may not necessarily be the best choice for the person with diabetes.
- Exploring psychological wellbeing and diabetes distress of family members should be an area of future research.

Part C

Chapter 8 - A summary and general discussion of the qualitative studies, and the development of a Grounded Formal Theory (GFT)

Chapter 9: Study 4: GFT Validation

Chapter 10: Study 5: Development and Delivery of Pilot intervention and evaluation

Chapter 8: A summary and general discussion of the qualitative studies, and the development of a Grounded Formal Theory (GFT)

Chapter 8 – Chapter overview

The following section presents a review of the evidence presented in the previous chapters (3, 5-7). Subsequently, this evidence has been integrated together, into a process of developing a GFT.

8.1. Introduction

The previous literature discussed in the earlier chapters of this thesis has offered an understanding of the issues and contributing factors that SA people with T2D experience. Indeed, the contribution of the previous research has been used to provide an insight into SA population (*Chapters 2 & 3*).

Each of the GT frameworks presented within the qualitative studies of this PhD (*Chapters 3, 5, 6 & 7*) have addressed a research question focusing on a specific perspective of diabetes self-management in SA' population: The meta-synthesis considering self-management behaviours of patients through a reanalysis and reconstruction of the previous evidence-base; health professionals perspectives of providing T2D to SA patient cohorts; patients perceptions of receiving T2D care, and; finally family members perceptions of supporting a significant other with T2D.

Each study applied GT methods (such as constant comparison) and claimed to offer robust frameworks and theoretical explanations for the findings. Indeed, each study focused on specific participant cohorts, and thus reached theoretical saturation (Strauss & Corbin, 1998) (*Meta-synthesis, studies 1 & 2, Chapters 3, 5 & 6*) or data saturation (Glaser & Strauss, 1971) (*Study 3, Chapter 7*), independently.

Adding a further stage of development in this research process has integrated these new GT frameworks together to develop a Grounded Formal Theory (GFT). A GFT 'aims to provide a data-based, broad level meaning that can be applied to individuals experiencing a common phenomenon' (Kearny, 1988 pg. 180). A GFT presents a truly triangulated and holistic representation to understand the concept of self-management behaviours in SA with T2D (Kearny, 1988).

This chapter discusses the new evidence developed from the individual empirical research (*Chapters 3, 5, 6, & 7*) and overviews the development of a GFT to create a comprehensive and detailed answer the PhD research aim: 'To explore the understanding and self-management behaviours of SA individuals with T2D'.

8.2. Summary and general discussion of empirical studies GT frameworks:

Table 8.1: Summary of GT frameworks

Research studies (chapters)	Perspectives	GT core categories	Theoretical Discussion
Meta-synthesis, Chapter 3 A systematic review and meta-synthesis relating to adherence to T2D self-management behaviours within the UK SA population	Patients	Cultural identity Defensive Conflict	Conflict theory, (Janis & Mann, 1977) Cultural identity
Health professionals, Chapter 5 Qualitative study investigating health professional's perceptions and experiences of supporting diabetes self-management in SA patients	Health professionals	Health professional's reflections on SA patients Delivery of diabetes care Patient understanding and engagement with diabetes care	Social Norms Theory, (Perkins & Berkowitz, 1986)
Patients, Chapter 6 Qualitative study exploring cultural factors in diabetes self-management amongst SA patients	Patients	Patient-centred care	SRM (Leventhal, Meyer & Nerenz, 1980) HBM, (Rosenstock, 1974) Communication Theory (Watzlawick & Beavin, 1967)
Family members, Chapter 7 To explore the experience, attitudes and views of a family member or friend involved in the care of SA patients with T2D	Family members	Family role Diabetes seriousness + Acceptance	Social Norms Theory (Perkins & Berkowitz, 1986) Social Comparisons Theory, (Festinger, 1954) SRM (Leventhal, Meyer & Nerenz, 1980)

8.2.1. Meta-synthesis of Self-Management Behaviours (Chapter 3)

Although the literature review (*Chapter 2*) identified broad issues around T2D self-management in the SA population, the individual research papers did not give rich insight into specific patient behaviours (relevant to SA with T2D). Subsequently, the meta-synthesis reciprocally translated the findings from published qualitative empirical studies into a new interpretation, which offered a robust and combined qualitative analysis (*Figure 8.1*). This synthesis was presented through a saturated GT framework.

A synthesis is not merely a review of previous literature, but the reconfiguration and re-analysis of data combined to create a new understanding. This meta-synthesis adopted a CIS methodology (Dixon-Woods et al., 2006) and re-analysed the findings from previous literature to create a new, high-order understanding of the meaning of diabetes self-management for SA adults.

The meta-synthesis systematically reviewed and synthesised the previous qualitative evidence-base on T2D self-management behaviours within the UK SA population. It highlighted the concept of cultural identity as a relevant construct towards self-management behaviours in SA T2D patients. It is noteworthy that although cultural identity itself is not a new psychological construct, it has not been previously discussed in T2D qualitative literature (e.g. Lawton et al., 2008, Patel & Lliffe, 2016) or indeed other published reviews (Fleming & Gillibrand, 2008; Sohal et al., 2015) exploring T2D self-management specifically in the SA population. With reference to the GT framework presented (*Figure 8.1*), the core synthetic constructs (Cultural Identity & Decisional Conflict) were influenced by the second-order constructs (Daily lifestyle/ roles influence behaviour; Doctor-patient relationship & Beliefs and Implementation). The outcome of the synthesis, which was directed towards the concept of Defensive Avoidance (Janis & Mann, 1977). Defensive Avoidance (Janis & Mann, 1977) suggests that people manage their diabetes through a process of decisional conflict, for which, individuals have to learn to handle such conflict, and often this occurs through choosing the decision (behaviour) which minimises the conflict and disruption to their daily lifestyles or T2D the most.

Together these constructs formed additional unanswered questions relevant to self-management behaviours, such as how do health professionals personalise T2D to take account of culture for patients T2D self-management behaviours, and what are the mechanisms which influence patients self-management behaviours (rather than allude to possible issues).

The theoretical discussion of the synthesis, focused on the understanding of Cultural Identity, suggesting that that the SA population managed internal conflict switching between aligning (their psychological, social and behavioural activity) towards their cultural identity or, alternatively towards their diabetes identity. For SA individuals the concept of cultural identity was found to have a strong influence on their lifestyle behaviour, more so than their acceptance of diabetes as a defining identity. When conflict existed, individuals typically defaulted towards cultural identity values, rather than T2D needs (or if conflict remained unresolved) and this often resulted in specific T2D avoidance behaviours. SA patients with T2D justified their (avoidance) behaviours through (external) beliefs such as believing their T2D onset and management was ‘Gods will’ (Lawton et al., 2008), rather than acknowledging a sense of personal responsibility (and internal control).

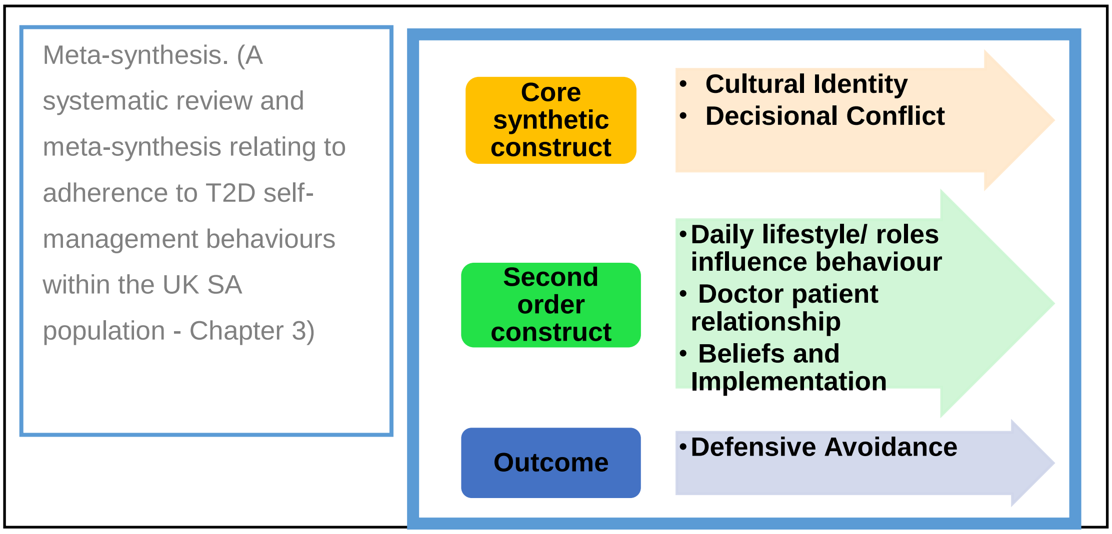

Figure 8.1: Meta-synthesis GT framework - Model of cultural-versus-health conflicts

It is important to note that previous research (Lawton et al., 2008; Jepson et al., 2012; Patel et al., 2014) has acknowledged ‘culture’ may impact on self-management behaviours but this, as a concept itself, has not been explored further. ‘Cultural identity represents a coherent narrative, a clear subjective knowledge and understanding of a group's values, norms, and characteristics, no matter how complex these shared elements might be’ (Usborne & Taylor, 2010, p. 885). Culture has been identified as a contributing factor to aspects of diabetes management (Carr, 2012; Emadian, England & Thompson, 2017), and previous research has recommended that cultural sensitivity should be considered in healthcare delivery (Boneham & Sixsmith, 2006; Lievesley, 2010; Szczepura, 2005). However, it was not clear how to implement or achieve cultural sensitivity in

T2D care, especially within the SA population. It was also not clear how cultural sensitivity varied across and within ethnic minority groups.

Previous empirical research has explored self-management behaviours from a patient-focused perspective (*e.g. see meta-synthesis Chapter 3 and patient study Chapter 6*). Although to date, there has been limited research investigating the views of health professionals, and a dearth of research examining the experiences of patient's significant others (family/friends).

8.2.2. Health Professionals (Chapter 5)

Empirical Study 1: Investigated health professionals’ perceptions and experiences of supporting diabetes self-management in SA patients. This study established that although the patient primarily managed their T2D, health professional’s experiences of engaging people with T2D, also have a significant influence on a patient’s management. The findings from this study highlighted the complex nature of the health professionals’ relationships delivering diabetes care and, drew attention to the specific difficulties that exist beyond standard diabetes care for SA people with T2D (*Figure 8.2*).

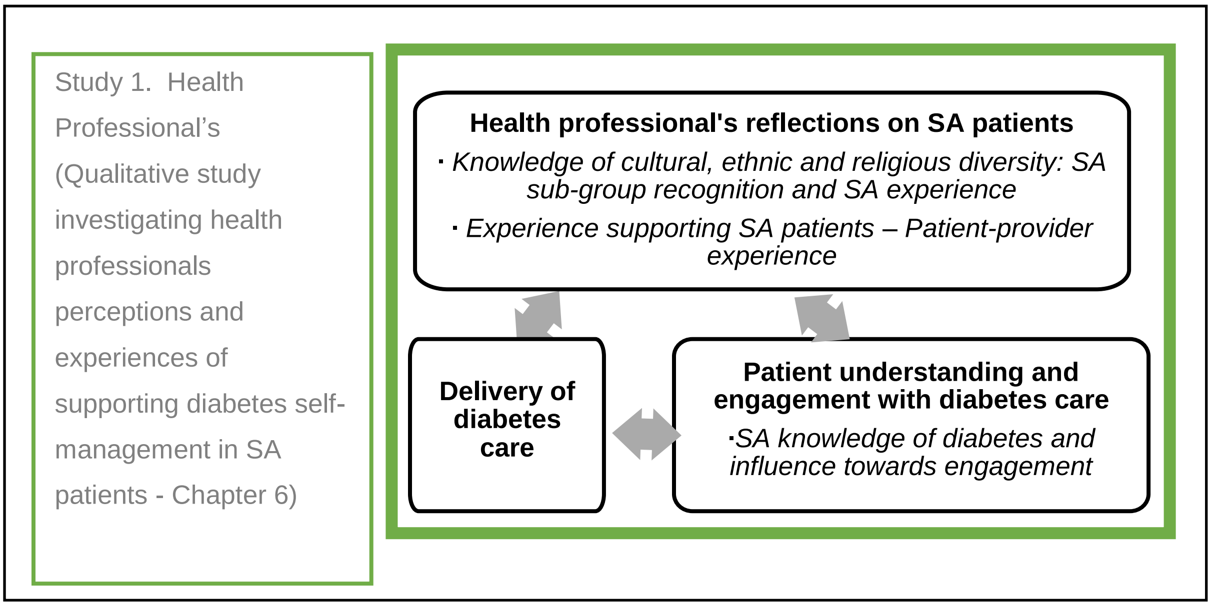

Figure 8.2: Study 1 GT framework- Cultural conflict in the delivery of health service

Health professionals' reflections suggested that their own ethnic bias influenced information delivery and thus made it difficult to target specific patient needs. Figure 8.2 presents a GT framework of the findings from study 1 (*Chapter 6*). Within the categories presented, health professionals were able to reflect on the differences that may exist in patients from an SA ethnicity compared to white Caucasian ethnicity. Although it is noteworthy that health professionals in general (regardless of their own ethnic status) had limited recognition for the variation that exists within SA groups, as a heterogeneous population. There was recognition that the relationships held between health professional and patient influenced recognition or acceptance of advice, and this was influenced by the health professionals' own perspectives (bias's) towards SA culture (and in part influenced by their own ethnicity).

The category of patient understanding and engagement with diabetes care highlighted that clinical consultations between health professionals and patients focused on providing diabetes information, but the integration of cultural/religious needs of the patients were rarely considered. Knowledge of culture was explored. However, health professionals had superficial knowledge about the SA population and categorised them as one group, when in reality, there are a number of sub-groups that exist within the SA umbrella. Comparisons between Caucasian and SA populations were made, and this may be due to the fact that the ethnicity of the health professional can also influence diabetes communication.

The SA population are a heterogeneous group, and these sub-groups vary in attitudes, knowledge, experience and beliefs, and these are factors that should be considered for successful diabetes management. The lack of recognition, of the heterogeneous nature of the SA population, was highlighted by the health professionals, most of whom, had not previously received any culture-specific training. This was particularly relevant for Caucasian health professionals who often relied upon other colleagues (who were SA themselves) to deal with SA patients or to advise them appropriately. However, this strategy made assumptions that the SA health professional was fully knowledgeable of the heterogeneous nature of the SA population. Although this strategy itself could lead to additional assumptions and stereotypes, given the SA health professional, still may not explore the SA patient’s needs (relevant to their culture) given the heterogeneous aspect of the SA population remains overlooked.

As discussed above, three core categories which emerged from this study: Health professional's reflections on SA patients; Patient understanding and engagement with diabetes care and; Delivery of diabetes care. Ultimately, health professionals suggested that targeting SA people with diabetes health beliefs and identifying core barriers to effective T2D self-management was challenging.

The theoretical discussion for this study referred to Social Norms theory (Perkins & Berkowitz, 1986). Typically, health professional did not raise issues relating to culture and religion, given these are sensitive topics, which need to be addressed without raising offence. There was an overemphasis on (foreign) language as a communication barrier for patients from SA decent. Language issues were almost used as an excuse towards a patient’s lack of understanding, rather than the health professional exploring actual understanding and personalising care to take into account individual ethnic, religious, or social-cultural influences.

The unique contribution to new knowledge here is that this is the first study, to our knowledge, which has explored health professional’s experiences and perceptions of diabetes self-management in supporting SA patient groups. This highlights that health professionals need to improve their communication with SA patients with T2D, so to acknowledge patients individual care needs.

8.2.3. People with Diabetes (Chapter 6)

Empirical Study 2: Explored cultural factors in diabetes self-management amongst SA patients. Previous research has considered patient perspectives on T2D self-management; indeed, the meta-synthesis reviewed this literature. However, it is noteworthy that previous research has been limited by the definition of SA, as either a homogenous group, in which individuals are grouped broadly into an SA category (e.g. Gumbler, 2014; Jepson et al., 2012; Macaden & Clarke, 2006; Macaden & Clarke, 2010) or has considered specific SA subgroups only (e.g. such as Bangladeshi cohorts, Choudhury et al., 2009; Greenhalgh et al., 1998). This study attempted to recruit SA individuals from various sub-groups, to represent the SA population within the North-West of England, including Indian, Pakistani and African participants (see introduction chapter for a description of SA population subgroups) and represents the heterogeneous nature of the SA population. This research suggests that specific cultural and religious nuances exist within the SA sub-groups (e.g. between Hindus and Muslims). Indicating that these differences (i.e. beliefs, experiences, cultural, religious needs, behaviours and expectations) influence patients' perceptions, understanding, acceptance and engagement with healthcare advice relating to their on-going diabetes self-management. Overall, patients did not think that health professionals understood their individual needs (this was echoed in study 1 via health professionals who did not acknowledge such diversity within the SA population) (*Figure 8.3*).

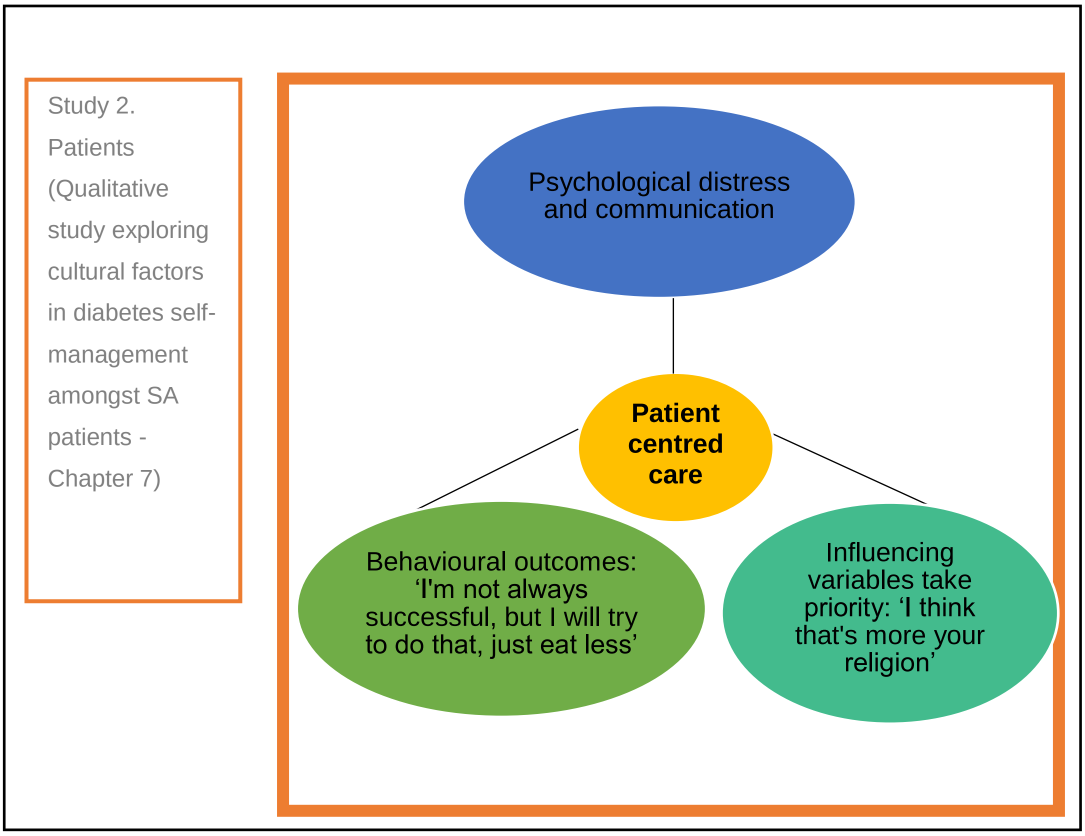

Figure 8.3: Study 2 GT framework - Framework of patient-centered care

The category of psychological distress and communication highlighted that at diagnosis (timepoint), patients experienced various emotions which contributed to psychological distress. Psychological distress at the point of diagnosis is not a new concept (Gask, Macdonald & Bower, 2011). Previous research has suggested people with T2D pose a risk of facing psychological distress due to the emotional aspects involved in diabetes management (Fisher, 2014). It has been highlighted that if psychological distress is not captured and supported early, it can lead to poor diabetes control (Chew, Shariff-Ghazali, & Fernandez, 2014). In this research, the underlying causes of patient's psychological distress appear to have not been investigated, and thus patients reported not receiving guidance (diabetes advice) personal to them. Moreover, this lack of investigation surrounding their diabetes distress contributed to ongoing cultural-identity vs diabetes conflict. These difficulties were also influenced by cultural and religious expectations, that patients subsequently managed (Dennick, Sturt, & Speight, 2017).   Long-term psychological distress appeared to manifest through defensive avoidance behaviours and influenced their T2D self-management (most often negatively) (Fisher, Gonzalez, & Polonsky, 2014). Despite clinical guidelines (NICE,2015; 2017) and previous literature in diabetes (*Chapters 2 & 3*) emphasising the importance of patient-centered care, this study draws attention to specific components that are important to SA individuals but, according to our research are not explored in clinical practice

The next category Behavioural outcomes: ‘I'm not always successful, but I will try to do that, just eat less’, highlights that although NICE guidelines suggest diabetes care should take account of individual’s personal circumstances such as cultural needs, more specifically SA dietary needs. For example, this study suggested that SA dietary practices were overlooked by the health professionals and the dietary advice promoted for T2D management was generic and more aligned to Caucasian diets, and as such dietary advice, in particular, was more likely to be ignored or misinterpreted.

It is important to distinguish culture from religion, as cultural dimensions, may influence psychological processes. For example, SA women with diabetes are typically dominant in the kitchen (taking on family cooking and house management responsibilities), if they have specific knowledge about the content of cultural foods they can then adapt their diets accordingly. Some participants in study 2 (*Chapter 6*) reported that they reduced oil and salt consumption (following generic T2D dietary advice), and ‘reducing’ consumption may be perceived as a positive behaviour change. However, given the style of SA cooking, this reduction may be minimal, and the person (family) may still consume very large amounts of salt and oil, which remain significantly above the dietary intake thresholds recommended. SA (women) have some misconceptions about healthy eating, cooking practices, and unless these beliefs are addressed, it is unlikely that SA patients will significantly change their dietary intake, in line with T2D advice. There is a need explore how SA patients (and their family members, especially those responsible for cooking and eating behaviours) can be supported to enhance their knowledge and possibility practice skills to change their cooking and dietary behaviour.

The third category ‘Influencing variables take priority: ‘I think that's more your religion’, highlighted the religious diversity of SA patients, and flags how religious beliefs impact self-management behaviour. Specifically, there were differences in beliefs, experiences and practices of patients depending on their religious status and thus cultural beliefs, which may have been employed to act as barriers to engaging with health professional advice and thus impacting on their diabetes self-management. For example, African Muslim participants appeared to be more likely to adjust their T2D management appropriately towards fasting behaviour, whereas Indian Muslims reported being stricter with their religious fasting obligations, and hence were more likely to omit their T2D medication.

The theoretical elements of this study considered the HBM, Communication theory and SRM. Combining these theoretical discussions suggested that psychological processes influence perceptions of patient-centered care and therefore influences patient's self-management behaviours. In addition, to considering the individual psychological processes which overlap with such theoretical models, the unique contribution of this study suggests the role of ethnicity, religion and social-cultural factors also impact on behaviours, specifically here T2D self-management. Moreover, the findings which exposed the nuances that exist in understanding, perceptions, experiences, and lifestyles, within and across the different SA sub-groups, flag a need to further consider individual patient needs in clinical practice.

8.2.4. The family of those with Diabetes (Chapter 7)

Empirical Study 3: Explored the experience, attitudes and views of family members involved in the care of SA individuals with T2D. The findings from this study suggested that the family played an important role in diabetes management as they influence the patient's behaviour. Their influence occurred in different ways, depending on their position within the family (*Figure 8.4*). In line with previous research, it has been suggested that family members provide social and emotional support (van Dam et al., 2005). This study has further developed our understanding specific to the SA population. Overall it is noteworthy that (females) wives adopted emotional supporting roles, and daughters/brothers offered more practical knowledge-based advice. Despite clinical guidelines acknowledging the important role of family members supporting patients with diabetes self-management, there is a paucity of previous research that has explored this topic, especially within the SA population.

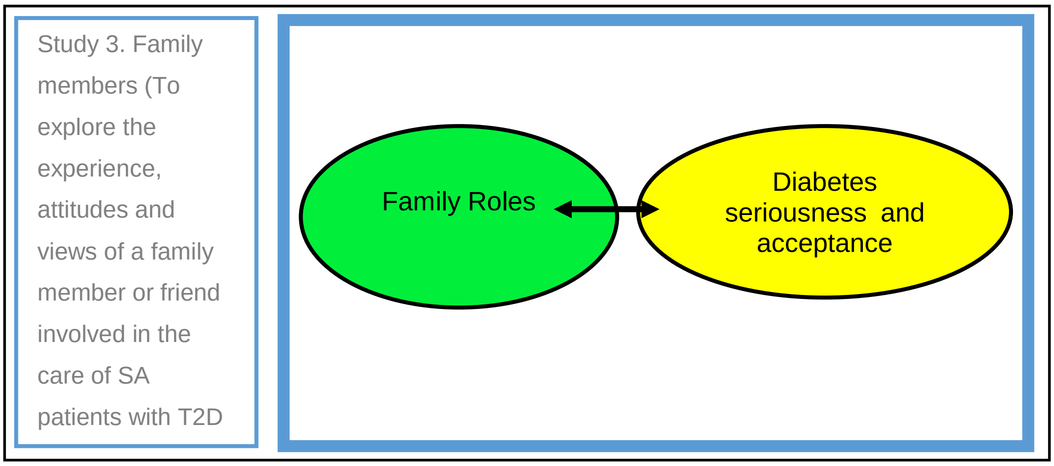

Figure 8.4: Study 3 GT framework - Roles, seriousness and acceptance model

Family members tried to make sense of the T2D and made comparisons to other health conditions, such as mental health or heart disease which were both considered to be more serious than T2D. These perceptions considered T2D as a less serious disease meant that family members did not get involved or offer support as much as they would have for other conditions (could have/ should have offered). Family members reported that there was lack of resources available for them to gain a better understanding of diabetes, and as such this lack of information, may be interpreted by family members that the condition does not require their support, understanding or attention.

Findings were discussed in the context of Social Norms Theory (Perkins & Berkowitz, 1986) and SRM (Leventhal, Meyer & Nerenz,1980) suggesting that family members accepted the condition as a normative development for people in their culture (T2D is considered a common and accepted condition within the SA population).

Family members acknowledge that often SA people have multiple conditions. Indeed in study 2, most patients reported having co-morbidities, hence it was perceived that diabetes was not a serious condition, compared to the patients co-morbidities, such as depression. Conditions such as depression were deemed to require more social (family support), whereas T2D was considered a ‘lived with’ condition. The unique contribution of this study provided insight into the different roles family members used to support patients with T2D. Ultimately family members are able to offer practical and emotional advice, which can positively or negatively impact on a patient's self-management behaviours. Positive influences included family members engaging in healthy lifestyle advice and attempting to motivate the T2D patients to engage in clinical advice received and become proactive in lifestyle change behaviours (healthy eating/ promoting physical activity). However, family members could also negatively influence a patient’s T2D management, particularly if behaviour conflicted with social-cultural or religious norms (such as not participating in religious celebrations or fasting; if the family member felt such participation was more important than adhering to clinical T2D advice they would discourage the patient to do so). Moreover, family members identified that there was a lack of engagement with them via healthcare services (they did not feel involved in the patients T2D care) and they also acknowledged a lack of resources regarding their role in supporting a person with T2D. Consequently, family members knowledge of T2D was variable. It is crucial to consider how family members can best be supported to understand T2D better but also how they but also how they can offer practical and emotional advice.

8.3. Introduction to GFT

As described in the qualitative study discussions, the concept of diabetes self-management is complicated, and many factors influence how people with T2D engage in such behaviours. The perspectives of various stakeholders involved in diabetes care (health professionals, people with diabetes and their family members) are important to understand.

Glaser and Strauss (1987) suggest that a GFT can be developed for a higher order understanding of existing GT frameworks (Eaves, 2001; Finfgeld, 1999; Kearney, 2001). GFT is defined as “suited to study of phenomena involving processes of contextualised understanding and action” (Kearny, 1988, p.180). The process for developing a GFT consists of applying coding, constant comparison and theoretical sampling to existing GT analysis (Glaser, 1978; Kearny, 1997; Kearny, 2001; Strauss, 1987). The individual GF frameworks presented within this PhD (meta-synthesis and empirical studies 1-3) have been merged (*Figure 8.5*) to offer a holistic triangulated and integrated theory covering multiple-perspectives (hence a GFT is a more advanced qualitative methodological process, and use here presents a stronger more comprehensive consideration of the research question). The development of the following GFT attempts to represent a genuinely saturated approach to explore the understanding and self-management behaviours of SA individuals with T2D, and thus the GFT as a whole seeks to satisfy the aim of this PhD investigation.

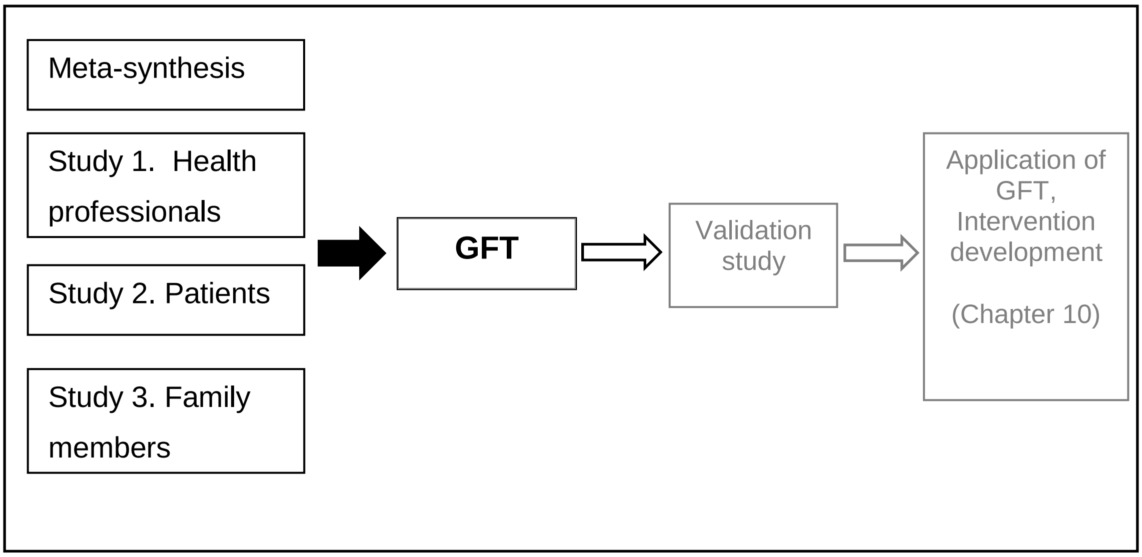

Figure 8.5: GFT development

8.4. Development of GFT

The following outlines the procedures followed to develop this GFT. Core categories were extracted from each of the previous GT frameworks (*Chapters, 3, 5-7*) and further GT analysis was applied during the integration process (Kearney, 1998; Strauss, 1987).

8.5. Analysis

8.5.1. Analytical procedure (Kearney, 1998; Strauss, 1987)

The GFT analysis focused on the phenomenon of exploring T2D Self-management behaviours from multiple perspectives (that of the health professionals, patients and family members).

The data used to create this GFT was from the GT frameworks presented in the meta-synthesis and empirical research chapters (which each individually focused on specific participant groups to answer sub-questions relevant to the PhD aim (Chapters 2, 5, 6, & 7). Data were extracted from each of the GT frameworks and re-coded to gain a higher-level perspective of diabetes self-management behaviours in SA population (*Appendix 8.1*). Key ideas were gathered into a temporary framework where each idea was modified into a meaningful concept (*Appendix 8.2*). Across the analysis (inclusive of all studies) memos were written making links between evidence (*Appendix 8.3*). Constant comparative analysis was carried out, and new axial codes were clustered into new GFT categories (*Figure 8.6*). Once these new categories were identified, the relationship between these categories promoted further selective coding and the emergence of a GFT. Upon development of the GFT additional theoretical sampling was completed as part of a ratification process. Glaser and Strauss (1965) recommend four elements to ensure validity in the development of a GFT (*See subsequent Chapter 9, a GFT validation study*). These four elements include: Fit (how the concepts closely represent the research question); Relevance (assurance that the categories emerged are relevant); Work (ensuring the theory can explain and interpret what is happening to answer the research question), and; Modifiability (a flexible theory that could be altered with new data). See subsequent validation study, (*Chapter 9*) for details on how this theoretical saturation (Strauss & Corbin, 1998) and validation of the GFT occurred.

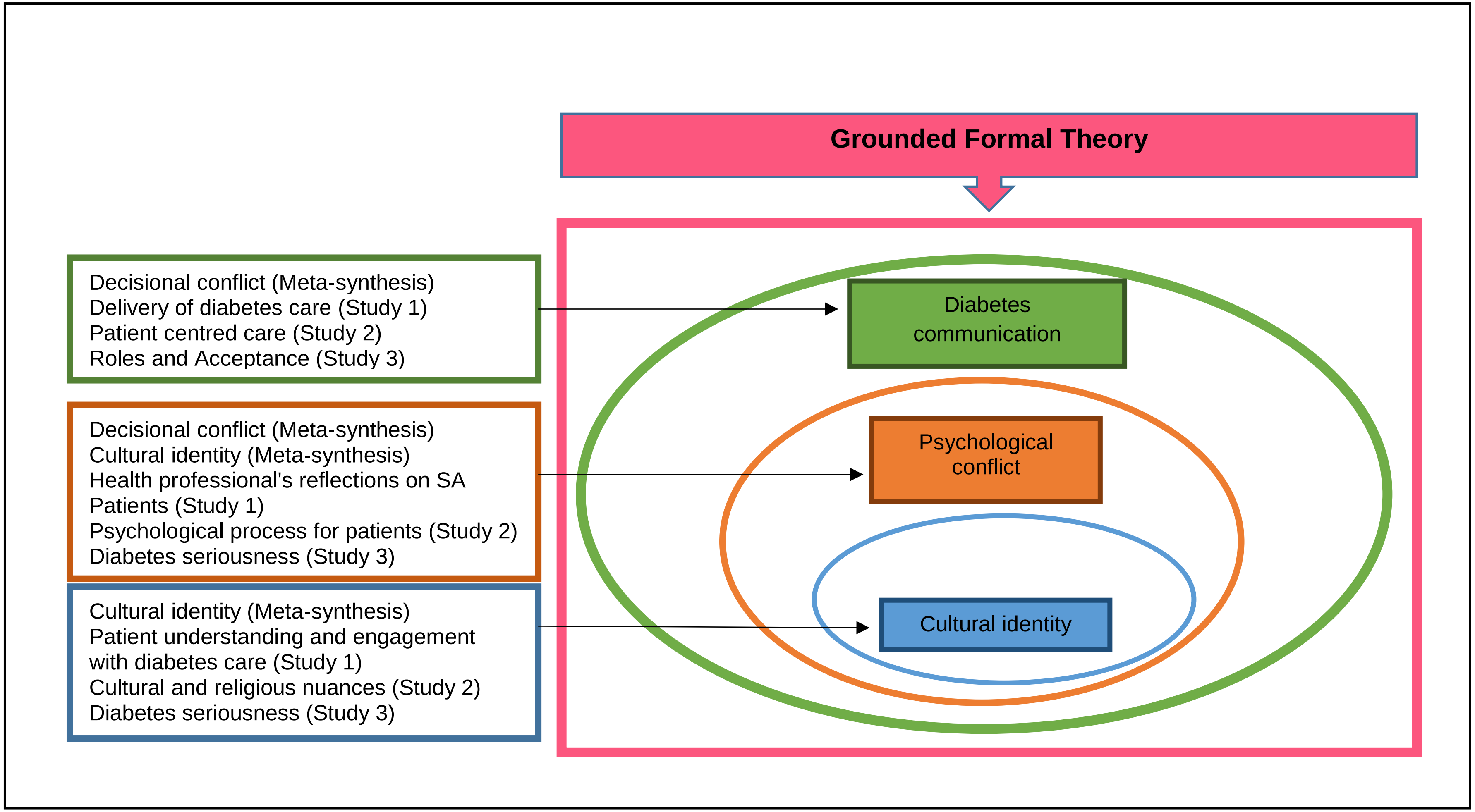

Figure 8.5: GFT model

The GFT overlays the mapping of the theoretical constructs and the commonalities presented across the PhD research discussed earlier (*Table 8.1*). The three high-order constructs presented in *figure 8.6* which interact to form the GFT:

Higher order construct 1 (Diabetes communication) was informed by the categories; Decisional conflict (Meta-synthesis); Delivery of diabetes care (*Study 1*); Patient centred care (*Study 2*); Roles and Acceptance (*Study 3*).

Higher order construct 2 (Psychological conflict) was informed from Decisional conflict; (Meta-synthesis); Cultural identity (Meta-synthesis); Health professional's reflections on SA patients (*Study 1*); Psychological process for patients (*Study 2*); Diabetes seriousness (*Study 3*).

Higher order construct 3 (Cultural identity) was informed from; Cultural identity (Meta-synthesis); Patient understanding and engagement with diabetes care (*Study 1*); Cultural and religious nuances (*Study 2*); Diabetes seriousness (*Study 3*).

Together these constructs interact to form the GFT. The following text provides context for each of these higher order constructs

8.5.1.1. Diabetes Communication

The concept of diabetes communication highlights the importance of how dialogue is delivered by health professionals and received by patients. This higher-order construct communication, considers what, how, why, when and by whom diabetes information is provided, how this communication of information is received by patients and examines the impact of this communication process of patient self-management behaviours (Bos-Touwen, Trappenburg, Van Der Wulp, Schuurmans, & De Wit, 2017). Overall issues with communication was a generic re-occurring concept which was considered throughout the empirical research and has formed a core construct within this GFT.

Communication between patient and health professional has been identified as an issue and a key topic that should be focused on as a healthcare skill (Linetzky, Jiang, Funnell, Curtis, & Polonsky, 2017). Specifically, in the SA population (foreign) language communication has been identified as an obstacle for patient interaction with health professionals (*See Chapter 1 for the diversity of the SA population*). While there have been attempts to mitigate such language barriers, during health care consultations, by having language translators or interpreters, such methods limit patient-health professional interaction (Hadziabdic, Heikkilä, Albin, & Hjelm, 2011; Pearson & Escott, 2010). Communication is an essential element of healthcare delivery, it needs particular attention as it offers the foundation of knowledge transfer better the health professional and the patients, and acts as a gateway to raise concerns and address any issues that a patient may experience, more specifically effective communication may help to identify and resolve any psychological conflicts which exist. The findings highlight that health professionals may benefit from taking a different approach in their delivery of T2D care, to break down communication barriers, by focussing on psychological individual’s needs (which specifically consider their health beliefs and cultural identity rather than making generalised assumptions of being ‘SA’). In addition to basic health professional-patient communication and knowledge transfer.

Diabetes communication was also influenced by patients health beliefs, specifically here patients had made upwards and downwards comparisons (Festinger, 1954, social comparison theory is also relevant here), whereby if a patient made comparisons to others with T2D as coping well, despite not engaging in the recommended T2D self-management behaviours, or if the patient had made a comparison between T2D and other health conditions such as cancer, heart disease or mental illness, patients would not perceive T2D as a serious condition, and hence may not ask questions during consultations, may not seek clarification or indeed may not accept (or trust) the information offered by the health professional.

This perspective was further supported by the family members (*Study 3*) which also presented misunderstandings of T2D and their interactions (communications) with patients may have influenced the health-professional patient relationship. Negative or non-supportive communication from family members may have a detrimental impact on the patient’s self-management behaviours (and the health-professional may be unaware of these views given the limited (non-existent) engagement with family members with a patients T2D care.

NHS England has recently published a position statement highlighting the importance of communication. This statement has been co-created with people living with diabetes and their experiences. Ultimately, this statement suggests that language used by health professionals’ influences outcomes.

This document has provided guidance and examples on how to deliver positive interactions, for example, positive language increase confidence and negative language can be seen as hurtful (Cooper, Kanumilli, Hill, Holt, Howarth, Lloyd, et al., 2018). This has been based on experiences from patients and how they perceive health care interactions. Applying psychological theories into practice can enhance healthcare interactions as it can help health professional better understand the psychological processes patients face when they are receiving advice.

However, while this communication document is a step in the right direction and acknowledges the difficulties around diabetes communication. There is still significant work required to improve the psychological processes involved in diabetes care. Moreover, despite this document acknowledging the need for improvements in diabetes communication generally, it does not address the ethnic, religious or social-cultural needs of patients with diabetes and thus highlights the need for further consideration of the GFT presented here within this PhD.

8.5.1.2. Psychological Conflict

Within the GFT the second construct of “Psychological Conflict” explored how individuals manage conflict. Specifically, in this context, it suggests that SA people with T2D manage their diabetes in line with their identity, which influences their subsequent behaviours. This construct was derived from the following core categories (Decisional conflict; (Meta-synthesis); Cultural identity (*Meta-synthesis*); Health professional's reflections on SA patients (*Study 1*); Psychological process for patients

(*Study 2*); Diabetes seriousness (*Study 3*). When conflicts, for example, those related to dietary intake or religious (fasting) are created due to the person with T2D not perceiving (or indeed receiving) T2D information aligned to their (health and cultural) beliefs, this creates a direct conflict with their diabetes acceptance (adherence) and often has a negative impact on the recommended self-management behaviours. Such difficulties (conscious or unconscious) manifest into psychological conflict (which often remains unresolved but are diminished by the patient by making decisions on how to manage these conflicts into their daily lifestyles). Such conflicts are a balance between managing a patient diabetes-identity versus their cultural identity.

Health professionals did not appear to acknowledge or explore such cultural-diabetes identity conflict, and thus the psychological needs of the SA person with T2D were not investigated. For example, at diagnosis, it was reported that patients felt shocked and this was missed in consultations. These psychological responses are significant as they influence decisions. Active health professional-patient communication processes which encourage the individual with T2D to express such conflict, if discussed and work through with the health professional, could help to minimise such conflict and thus improve the delivery of care, and subsequently improve patient’s implementation of self-management behaviours.

Overall there was a perceived lack of person-centered care, while health professionals implied they offered culturally tailored advice to their best knowledge, there was recognition that this advice did not always meet individual needs. The cultural advice offered was typically guided from health professionals previous experiences of working with SA population groups, as opposed to having received cultural relevant training or working in detail and assessing individual SA needs.

Health professionals acknowledged how culture and religion can be a sensitive and timely topic to bring up and as such these topics may be avoided. Study 2 (*Chapter 6*) further verified this view, whereby patients expressed that they did not always receive the advice personal to them (despite NICE guidelines recommending this is a crucial part of T2D healthcare delivery). In study 3 (*Chapter 7*) family members appeared to influence (positively or negatively) patients' behaviours by providing either emotional or practical support, but due to lack of resources, advice and guidance, this support was often ad-hoc and unstructured. Effective communication between the patient and health professional can lead to better clinical outcomes as it can help motivate people with diabetes to achieve their goals (Alzaid, 2014).

8.5.1.3. Cultural identity

The third higher-order 'Cultural identity' construct addressed the role of cultural identity influencing the acceptance and management of T2D in SA patients. This construct was derived from the core categories related to Cultural identity (Meta-synthesis) (*Study 1*) Cultural and religious nuances (*Study 2*) Diabetes seriousness (*Study 3*). For any patients diagnosed with T2D, or indeed any long-term health condition, the label (of living with diabetes) becomes part of who they are, and it impacts on their daily lifestyle and behaviours. The decisions patients make with regards to their self-management behaviours, as informed by the associated meaning of living with T2D (diabetes identity) is a vital aspect of accepting T2D as a condition. However, for SA individuals the role of cultural (and social) acceptance, and therefore cultural identity may supersede that of diabetes-identity, and hence culture may be a significant aspect in delivering person-centered care for SA patient, although currently, this aspect of care appears not to be acknowledged by health professionals. Past research has highlighted that culture should be a key focus of person-centered healthcare (Holt, 2012; Wright, & Buchczyk, 2015). However, this GFT advances previous research, not only recognising the role of cultural identity for effective healthcare delivery but recognising that when this is not addressed decisional conflicts manifest which lead to avoidance strategies and have influenced both the health professional-patient relationship and communication but also affect long-term acceptance and effective management of T2D. For example, as highlighted in study 2 (*Chapter 6*) patients reported receiving no specific advice regarding the consumption of cultural foods, hence when they attended social, religious events such as weddings, patients opted to make changes to medication doses without seeking guidance from their health professional, through fear of being judged, misunderstood or told not to do it (and thus a patients interpretation of this message would be not to take part in the social-religious events which would be unacceptable). This viewpoint was echoed by family members (*Study 3*) who often negatively influenced a patients T2D self-management decisions by encouraging them to integrate into SA lifestyles and not to adopt health professional recommendations.

Health professionals themselves were mindful of traditional religious festivals, especially Ramadan with reference to the religious fasting obligations, although their knowledge of regular ‘fast and feast’ activities beyond this monthly fasting behaviour during Ramadan, as an example, were limited. Health professionals had limited knowledge in the field and thus limited skill in communicating with SA patients to help them overcome diabetes- cultural identity conflicts which exist.

8.6. Discussion

This GFT as a synthesis of the empirical research has considered various psychological and cultural issues. Hence the GFT offers a holistic account of T2D management from a heterogeneous sample of SA people with T2D. This is a unique contribution to knowledge, as previous T2D evidence has focused on either psychological or cultural issues only, and these concepts have not previously been combined. Previous studies have explored the practicalities of diabetes self-management employing a top-down approach to research where the focus was from a service level. There has been an attempt to understand the behavioural strategies towards adherence to self-management, such as exploring factors that influence diabetes management, i.e. cultural factors, religious beliefs. However, taking a bottom-up approach, coming from the patient and family members perspectives, has provided a deeper understand of the behavioural processes that are involved when patients engage with the T2D self-management strategies, i.e. diet, exercise, SMBG and medication.

Patients and family members referred to social comparisons throughout (Festinger, 1954). Social comparison theory (Festinger, 1954) can be used to explain how people try to make sense of diabetes as an ordinary, common health condition, how they evaluate others with T2D or indeed other health conditions (managing better or worse than others). These social comparisons often lead patients to adopt “normalising” behaviours, acceptable within their SA community (and social world/ family context). Patients want to be perceived as normal, they do not want to be judged (or discriminated against from their social community) and thus feel the need to enforce social norms, as promoted by friends and family. Ultimately these beliefs influence how patients manage their decisional conflict and result in deviations from the recommended self-care behaviours and advice provided by their health professional, and consequentially this can create diabetes distress, poor diabetes communication and sub-optimal self-management behaviours (hence poorer clinical outcomes in this population group). The findings form the basis for delineating the role of social comparison and social norms in self-management that can be beneficial for health professionals in tailoring advice and information, and indeed offering a person-centered approach to care, which is especially relevant to the SA patient group and the third order constructs of cultural identity and diabetes communication.

There has been little attention given towards psychological underpinnings, which can explain patients T2D management decisions and behaviours. Despite the past evidence of self-management in diabetes and the focus in some studies on SA population (*Chapters 2 & 3*), there has been a lack of evidence which has explored the culture specifically. Previous research or current health care interventions have been developed through a mainly Anglo Saxon orientation for a society that is predominately Caucasian (Kokab, Greenfield, Lindenmeyer, Sidhu, Tait, & Gill, 2017; Koshoedo, Paul-Ebhohimhen, Jepson & Watson, 2015; Zeh, Sandhu, Cannaby, Warwick, & Sturt, 2016). Thus current understanding and approaches to T2D health care for SA patient groups have not demonstrated the success and improvement in care provided (Quay, Frimer, Janssen, & Lamers, 2017). This GFT is the first attempt to bring together multiple concepts and multiple perspectives to create a truly comprehensive and meaningful understanding of the experiences of SA patients with T2D and how these experiences influence their T2D self-management behaviours.

Chapter 9: Study 4: GFT Validation

Chapter 9 - Chapter overview

The GFT is ratified via a validation study, which verified the findings from the development of the GFT moving from a theoretical perspective into a real-world evaluation. The validation process for the GFT occurred via two supplementary studies: A) A Patient Public Involvement workshop discussion community groups of patients with T2D and discussions with stakeholders (various health professionals) was carried out to ascertain their feedback on the understanding and usefulness of the GFT.

9.1. Introduction

In this PhD thesis, the selection of qualitative methodology rather than quantitative has helped to establish an open approach to theory development. The GFT presented in Chapter 8 has been constructed from the integration of evidence collated from a meta-synthesis of qualitative evidence, and three empirical research studies (*Chapters 3, 5, 6, 7*) exploring the understanding and self-management behaviours of SA individuals with T2D by triangulating the findings from multiple sources.

Using a GT qualitative approach across these studies has allowed the concepts and design to emerge from the data collected (Strauss & Corbin, 1998). Moreover, the use of GT is an appropriate methodology "when a phenomenon has not been adequately described, or when there are few theories that explain it (Henderson, as cited in Skeat & Perry, 2008, p. 97).

This GFT is, therefore, a theoretical model. While the focus of this theory is based on individual, intra-individual level processes to understand T2D self-management behaviours (an important aspect of understanding health behaviours), this theory has also (uniquely in T2D research) considered how these processes operate in practice, and how they are influenced by cultural, social and environmental contexts. Specifically, this GFT has focused on SA patients as a particular ethnic minority group, and within this, SA population, the GFT further explored the ethnic and cultural variation and heterogeneous nature that exists within this group. However, the next challenge was to consider how to translate the GFT beyond initial development and apply to clinically meaningful interventions or practice that may impact on future T2D care. As quoted from Green and Glasgow (2006) “if we want more evidence-based practice, we need more practice-based evidence” (p.126).

Hence, the purpose of the following validation study was to “provide a meaningful guide to action” (Strauss & Corbin, 1998, p. 12), and explore the GFT’s real-world application into healthcare (taking this theory into in real world, in real time contexts): i.e. did the presentation of the GFT make sense to those living with, or working with those, with T2D. This process aimed to develop external validity adding credibility, to increase the weight of the evidence for the GFT.

The overall objectives of this study were to:

Engage key stakeholders in the process of research validation, to ensure the GFT included a range of people to provide different voices, experience and perspectives on the evaluation and further development of the GFT. To offer those with T2D an opportunity to comment on technical research development in plain English, not use ‘NHS-speak’ or research jargon. To turn results of this research into action rather than remain as theory, and to seek the views of health professionals to ensure later buy-in into clinical practice.

9.2. Methods

The validation process for the GFT occurred via Patient Public Involvement (PPI) workshops occurring in the community with groups of patients with T2D and through discussions with key stakeholders (various health professionals) working within T2D services. PPI is defined as “being carried out ‘with’ or ‘by’ members of the public” not just “‘to’, ‘about’ or ‘for’ them” (INVOLVE, 2018).

9.2.1. Participants

Thirty SA participants diagnosed with T2D participated in one of three PPI workshops (October 2016). Participants were recruited through two General Practices and one community centre group in Bolton, North-West England. Ten health professionals (GPs, Practice Nurses, Policymakers, Diabetes Dietitian, Diabetes Specialist Nurse and Consultants) working in diabetes care discussed the presentation and findings of the GFT with the lead researcher through 1-1 discussions.

9.2.2. Procedure

The community PPI workshops were guided by an agenda to structure the session (*Table 9.1*) and adopted focus group methodology, aiming to bring together a variety of views at once (Krueger, 1988). Participants completed a demographic sheet (*Appendix 9.1*) and provided consent to take part. The discussions were flexible, with a basic structured conversation schedule, initially the participants were provided with an overview of the GTF, firstly introducing the primary findings from the four individual studies (*Chapters 3, 5, 6 & 7*) so that they could understand how the GFT had been constructed, followed by a subsequent presentation about the final GFT (*Chapter 8*). The participants were asked to give their opinions and thoughts regarding the GFT presented, and the researcher aided discussion regarding their understanding and thoughts about the model presented. The workshops were organised into short sessions so to not overwhelm participants. The presentation of the findings was explained carefully (accounting for health literacy of the community population and not assuming research language would be understood).

Table 9.1: Workshop Agenda

Workshop Agenda
Registration and tea & coffee
Introduction
Group session – each study discussed and reflections on group understanding.
Break
GFT presented to altogether
Group discussion
Take away actions
Thank participants and close

Conversational evidence (Given, 2008) was captured by hand-written field notes made by the researcher during the workshops; the decision to not use a digital recorder was made so that participants could speak freely and openly (Tessier, 2012). The on-site paper and pencil technique was adopted (Lavrakas, 2008). There are two different types of field notes that were utilised (Hamo, Blum-Kulka & Hacohen, 2004). The first type of a field note is recording the event chronologically where the researcher recognises and codes the data as the interview progresses (White, 1980) and the second type of field note is to summarise and reflect after the interview (White, 1980). According to Wengraf (2001), the content of the notes should capture feelings and emotions and should be converted to field notes immediately following the workshops (Sanjek, 1990).

Due to health professional availability (knowledge gained through previous experience of conducting research with health professionals, see *Chapter 5*) individuals working in a range of roles within diabetes services were contacted via email and telephone to request their involvement in this study. Health professionals were asked to provide feedback on the GFT during a one-to-one discussion with the lead researcher. The lead researcher made field notes and later collated with the community participant discussion notes to be analysed into key points for feedback and development.

9.3. Analysis

1.a. Community Participants with T2D

As a community group, participants with T2D reflected on the findings presented and discussed if they agreed with the theoretical explanations and considered how the frameworks aligned to their experiences of diabetes healthcare and their self-management.

Overall, the participants agreed with the theoretical presentation of the meta-synthesis and studies 2 (patients) & 3 (family members). They were in full agreement regarding personal psychological conflict, and overall a sense of miscommunication and lack of understanding of their condition (e.g. this was discussed in terms of lack of awareness and uncertainty of the causes of diabetes, there were a number of questions asked as to what caused diabetes, and most participants were not aware of diabetes aetiology. Due to this lack of knowledge, most were not aware of complications associated with not adhering to the diabetes management advice). Ultimately participants reflected on a number of misconceptions and negative health beliefs relevant to their T2D. It was acknowledged that they had received little support to challenge their beliefs or explore their understanding of T2D beyond practical based advice (e.g. how to take metformin).

In addition, the participants also accepted the framework presented within study one, which explored health professional perspectives. The issues with health professional-patient communication were recognised, and these participants reflect on their own experiences of not receiving specific culturally relevant advice, not disclosing information to health professionals (explicitly stating they didn’t ‘tell their nurse everything’) and had many unanswered questions regarding their condition (for which participants compared their stories and experiences with each other as part of the discussion process). Moreover, the participants highlighted the importance of social support (especially from family members) and acknowledged the limited support and advice received in how to engage family members in their T2D management. Moving beyond the presentation of the GFT, but taking this into account, the participants made suggestions on how to improve healthcare delivery which included: offering sessions to talk to other patients with T2D and providing family support sessions to help self-management behaviours. Participants requested practical suggestions to support the implementation of lifestyle advice (such as providing culturally sensitive cookery sessions and activity classes). Overall participants wanted improvement in their diabetes healthcare communication and support, specifically addressing how they could adjust to cultural nuances and recognise their psychological needs.

1b. Health Professionals

Health Professionals broadly agreed with the GFT and accepted the role of decision-conflict and defensive avoidance as key concepts. Although they suggested this needed further exploration, in terms of how to address and support patients to manage and change their conflict and avoidance-based behaviours. Overall health professionals were surprised at the variation in the T2D care needs of those from SA cultures. There was some concern, but acknowledgement, surrounding lack of knowledge of cultural nuances. Health professionals recognised their defensive response towards this sensitive topic. They accepted the importance and role of patient centred care, and had a basic appreciation of psychological needs, although skills in this area were general and no specific examples of how health professionals enquired about patient's psychological status or needs were provided. Health Professionals were keen to emphasise that care was tailored when possible, although they were unclear how to change their practices or communicate differently around these topics. In addition, queries regarding the role of social support were highlighted as important but not currently addressed systematically in care services, and again there was a call to provide healthcare providers with support on how to offer and promote the role of social support.

9.4. Discussion

The findings from this validation study demonstrate agreement with the concepts of the GFT presented from those living with and working with T2D. The model itself has not been amended because of this validation study.

However, this study has highlighted the need to integrate psychological support and advice into care processes. Improving patients' psychological understanding of their T2D could have a significant impact on their self-management behaviours (and attendance at appointments and may also improve health professional-patient relationships through the perception of better communication).

From this validation study, those living with T2D recognised the concepts and relevance of understanding T2D identity, severity, cause and timescale of the disease. These aspects influenced their coping behaviour and subsequent outcomes of their T2D self-management. Ultimately participants reflected on how their thoughts, feelings, and behaviours were entwined (Mann, de Ridder, & Fujita, 2013), although did not feel their healthcare team had recognised them. These concepts lend themselves towards health beliefs and of relevance here their self-regulation of T2D of behaviour, (SRM, Leventhal, Meyer & Nerenz, 1980). Moreover, in addition to general health beliefs, participants reflected on the role of health professional-patient communication (contextual factors) and the conflict which exists in managing decisions they make post consultation, this was especially pertinent to their cultural behaviour (cultural influences) and how T2D needed to be integrated into their ethnic-social worlds.

Overall, there was a consensus of approval from the health professionals for the individual GT frameworks (*Chapters 3, 5, 6, & 7*) and the GFT (*Chapter 8*) discussed. However, given the complexity of the topic and the complex nature of the GFT presented, stakeholders suggested a need for training to help understand the GFT and apply the constructs into healthcare practice, especially how to challenge patient's health beliefs and how to become more person-centered taking account an individual's cultural and ethnic backgrounds.

9.5. Conclusion

Together, the findings from this validation study support the GFT as a useful model to explain self-management behaviour in SA patients. In essence, as planned, this study provides a "meaningful guide to action" (Strauss and Corbin 1998, p. 12) and provides feedback from those in the real world (living with, and supporting those with T2D). However, as previously stated "if we want more evidence-based practice, we need more practice-based evidence" (Green & Glasgow, 2006, p.126) and as such this study highlighted the need to move beyond the evidence-based theory, and to find a way to implement these findings in T2D practice.

Chapter 10: Study 5: Development and Delivery of Pilot training intervention and evaluation

Chapter 10 - Chapter overview

This chapter provides an overview towards how the GFT has been applied in practice via a pilot training intervention involving health professionals working in diabetes. Subsequently, the GFT aimed to move from an evidence-based theoretical model into practice-based evidence using the GFT and validation study to implement into real-world practice. This chapter overviews the development of a pilot training intervention with health professionals. The focus of the intervention was uniquely informed by the GFT evidence-based and designed around the core constructs of cultural identity, person-centred care and health communication practices. The process of intervention development was also taken through a participatory research process to ensure real-world relevance so that health professionals could make use of and implement the training offered.

10.1. Introduction

As stated in the previous chapter (9): “if we want more evidence-based practice, we need more practice-based evidence” (Green & Glasgow, 2006, p.126). According to Glasgow, Lichtenstein and Marcus (2003), a number of factors contribute towards the gap between research and practice; these include lack of training, limited resources and insufficient feedback for the health professionals to use evidence-based practice (Green & Aarons 2011; Orlandi, 1987). In response, a participatory research study has implemented elements of the GFT into a training intervention to help health professionals to improve their delivery of diabetes care and consequently improve patient-communication, understanding and ultimately self-management behaviours.

In this context, as stated by Green & Glasgow (2006) rigorous theory testing occurs not in tightly controlled contexts, but rather in imperfect settings. This participatory research study (Cornwall & Jewkes, 1995) focused on improving health professional communication, cultural competency, improving psychological assessment and support required to ensure a truly patient-centred offer to individuals with T2D.

The following chapter presents the development of an intervention for health professionals who support patients with T2D in areas of high ethnic diversity. The target group of health professionals were GPs, practice nurses, dietitians and any other health professionals who had contact with people with T2D, from ethnic minorities. This chapter describes the phases of intervention development and delivery: which has included a 1) needs assessment, which was based on the new evidence created from the GFT, the validation study, as well as a supplementary insight study regarding health professional's cultural competency. 2) Content design and development, which considered the structure, teaching strategies and detailed content to be delivered. 3) Implementation, which adopted a participatory research approach of engaging in four cycles: Plan, Action, Observe and Reflect, with different participant groups to ensure the credibility and relevance of the training. Finally, phase 4) evaluation, occurred through participant evaluation, peer observation and self-reflection. Approval for the pilot training intervention and evaluation secured from the Liverpool John Moores University Research Ethics Committee (16/NSP/029) (*Appendix 10.1*).

10.2. Methods

Training intervention:

Bartholomew, Markham, Ruiter, Fernàndez, Kok, and Parcel (2016) suggested the following elements towards intervention development: (*Table 10.1*).

Table 10.1: Intervention development and mapping process

Phase	**Intervention Mapping step**	**Completed**	**Evidence**
Phase 1	0. Conduct a needs assessment	Literature search Interviews Online questionnaire	PhD research chapters 1-4
	1. Identifying which beliefs should be targeted by the intervention;	Interviews Online questionnaire	GT validation chapter 8
Phase 2	2. Select theory-based intervention methods	GT saturation chapters	
	3. Integrate methods and the practical applications into an organised programme	Pilot training Collect ideas from health professionals	
Phase 3	4. Plan for adoption, implementation and sustainability	Implement the training	
Phase 4	5. Generate an evaluation plan	Evaluation of findings	

10.2.1. Phase 1 - Needs assessment

The theoretical basis of this intervention was informed by the integrated GFT theoretical discussion and validation study (*Chapters 8 & 9*). This focused on the concept of cultural identity, psychological management and understanding of T2D from an ethnic minority perspective. The role of cultural identity aimed to help health professionals reflect on the patient’s psychological interpretations of T2D and thus improve their communication and delivery of care, and consequently, the patient may improve their self-management behaviours.

Recognising that health professionals were sensitive to issues around cultural competency (*as highlighted during validation study, chapter 9*). An additional needs assessment was conducted to enhance our understanding of health professional's knowledge of patient-culture. The aim of this was specifically to gain further insight into health professionals' knowledge, experiences and their training needs about cultural competency in healthcare.

Cultural competency- supplementary investigative study overview:

10.2.1.1. Introduction

In study 1 (*Chapter 5*), health professionals suggested that their own ethnicity and experiences around ethnic diverse populations influenced their knowledge and interactions with patients, relative to their diabetes. This cultural knowledge was also acknowledged as a limitation of the patient study (*Chapter 6*) which suggested that health professionals did not recognise person-centred care needs, due to the lack of cultural awareness. Furthermore, this concept was again highlighted as an issue during the validation study (*Chapter 9*).

A number of studies have employed quantitative methods to assess health professionals' views and attitudes regarding diabetes self-management (Anne & Larme, 1998; Sharp & Lipsky, 2002; Weinberger et al., 1984; Clark and Hampson, 2003; Bani-issa et al., 2015). Cultural training can enable the elimination of disparities and improve care (Betancourt, Green, Carrillo, & Owusu Ananeh-Firempong, 2016; Dogra, Reitmanova, & Carter-Pokras, 2010). A review conducted by Beach, Price, Gary, Robinson, Gozu, Palacio, et al. (2005), who collated findings of studies evaluating interventions to improve the cultural competence of health professionals. It was identified that cultural competence training (improving awareness of culture) could improve knowledge, attitudes, confidence and skills of health professionals (George, Thornicroft & Dogra, 2015). A study conducted by Alpers & Zoucha, (1996) compared the cultural competence and confidence by administrating The Bernal and Froman Cultural Self Efficacy Scale to two groups of senior nursing students, one group had received cultural content (N = 32) and the other group did not receive any cultural content (N = 33). The study found that the group who received some cultural training felt confident to deliver culturally sensitive care than the group who did not receive cultural training. Paez, Allen, Carson, and Cooper (2007), carried out a cross-sectional study to establish if there was a link between the cultural competence of primary care providers and the clinics where they work. Forty-nine primary care providers took part in an online survey, the results identified that staff with attitudes reflecting greater cultural motivation to learn were more likely to work in clinics with a higher percent of non-white staff, and those offering cultural diversity training and culturally adapted patient education materials.

None of the studies reviewed thus far focussed explicitly on SA patients; thus there remains a lack of quantitative evidence on health professionals’ views regarding diabetes self-management specifically in SA population (Bhui, Warfa, Edonya, McKenzie, & Bhugra, 2007; Brach & Fraserirector, 2000; Dogra & Wass, 2006).

10.2.1.2. Methods

10.2.1.2.1. Participants

This questionnaire study recruited a sample of health professionals and assessed in more detail their ‘cultural competence’ relative to their own ethnic status. A total of 79 health professionals working with people who have T2D completed the online questionnaire, 50 were excluded due to failure to complete up to 50% of the questionnaire. Therefore, the analysis was run on the 29 data sets of which 6 only completed 50%; these were not entirely excluded as statistical analysis allowed to systematically exclude the incomplete data sets from the analysis. The final sample consisted of six males and twenty-three females; of these 17 were white ethnicity, 11 were mixed/multiple ethnic groups, and one preferred not to say. Participant’s ages ranged from 18-64 and of these, the majority identified as being aged 45-54. These participants were grouped into ‘White Caucasian (WC)’ versus ‘Ethnic Minority (EM)’ categories.

10.2.1.2.2. Materials

Participants were administered two questionnaires (*Appendix 10.2*) 1) The Health Professionals Self-Assessment of Cultural Competency scale (HPSCC, Waugh, Szafran & Hanafi, 2011) which required health professionals to evaluate their own cultural knowledge, awareness, sensitivity, behaviours and cultural confidence. This questionnaire consisted of six sections; questions were rated on a scale from 1-6, to indicate how it best described the health professional’s agreement to that item. In addition, health professionals completed the Revised Illness Perception

Questionnaire' (IPQ-R, Weinman, Petrie, Moss-Morris & Horne, 1996) which was adapted to assess the health professional's interpretation of a patients cognitive representations of diabetes. This questionnaire uses two sub-scales one which explored diabetes Identity (38 questions) and one which explored diabetes cause (18 questions). The questions were presented on a five-point scale ranging from "Strongly Disagree" to "Strongly Agree".

10.2.1.2.3. Procedure

The questionnaire was completed online, via Qualtrics (Qualtrics, Provo, UT, 2016). The link of the questionnaire was promoted by supporters at Diabetes UK and various other organisations who sent it to out to their email networks. The questionnaire was also promoted via social media including Twitter and LinkedIn.

10.2.1.2.4. Ethics

Approval for the study was secured from the Liverpool John Moores University Research Ethics Committee (16/NSP/029) (*Appendix 10.3*).

10.2.1.3. Analysis and Results

A Mann-Whitney analysis was conducted on the subscales of the HPSCC, which revealed health professionals who defined themselves as Ethnic Minority (EM) status, had higher cultural competence scores (*Mean* = 14.73) compared to health professionals who defined their ethnicity as White Caucasian (WC) (*Mean* = 9.50) (*Appendix 10.4; Table 1*). However, this difference was not significant (p= 0.065) (*Appendix 10.4; Table 2*), although there is a trend towards relevance here it is however noteworthy, whilst not significant the sample size did not reach a power level of 0.8 (Hintze, 2008). Thus a Type1 error may have occurred.

Individual cultural competency subscales revealed no significant differences between health professionals own ethnicity and their 1) acceptance of the importance of equality in health care (WC mean = 11.25; EM mean =12.82, p>0.05); the patient cohort they interacted with, was not related to their own ethnicity (WC mean = 12.17;EM mean = 11.82, p >0.05). Compared to health professionals from WC status, health professionals from EM status reported greater knowledge about ethnicity and ethnic groupings (WC mean = 9.63; EM mean = 14.59). EM health professionals were more confident in their interaction with patients from different cultures (WC mean = 9.83; EM mean = 14.36) and believed that the cultural identity of patients influenced health care interactions (WC mean = 9.67; EM mean = 14.55). However, again, these differences were not statistically significant (p>0.05). However, EM health professionals were significantly more likely to recognise the role of 'personalising patient care based on cultural needs' in comparison to their WC health professional colleagues (WC mean = 9.21; EM mean = 15. 05, p<0.05) (*Appendix 10.4; Table 3*).

This supplementary study also explored health professionals' perceptions regarding SA patient's vs Caucasian patient's beliefs about diabetes and its management. Wilcoxon ranked analysis was applied to the IPQ subscales, which suggested that health professionals perceived that Caucasian patients were significantly more able to understand diabetes as a health threat (SA mean = 12.48, *SD* ± 3.832; Caucasian mean = 14.76, *SD* ± 3.471, p < 0.05). Moreover, health professionals also believed compared to SA patients, Caucasian patients had a better understanding of their diabetes, more likely to accept T2D as a chronic rather than an acute condition (SA mean = 20.76, *SD* ± 4.823; Caucasian mean = 22.66, *SD* ± 2.894, $p < 0.05$ (Appendix 10.4; Table 4). [* However, it is noteworthy this significance diminishes following Bonferroni correction $p > 0.001$].

10.2.1.4. Conclusion

It is acknowledged that the sample size of this supplementary study was small, although it is recognised that health professionals have demanding job roles and limited time and so this might explain the low response rate (Cottrell, Roddy, Rathod, Thomas, Porcheret, & Foster, 2015). However, it is noteworthy that a number of health professionals consented to the research and started to complete the questionnaires. While time available to complete the questionnaires may well have influenced their decision to participate, it is possible that due to the sensitive nature or possibly lack of knowledge on the topic of patient culture and ethnicity, that this caused the participants to withdraw from completing the full questionnaire. Anecdotal feedback from participants suggested that they did find the topic of the questionnaire difficult to comprehend (found the topic both sensitive and challenging. Thus it was easier not to consider the topic and not to complete the full questionnaire).

Overall, this data suggests that health professionals would benefit from specific support/training in helping SA patients to understand their diabetes and challenge their beliefs. This may benefit from developing their skills to recognise cultural variation in patient needs and how to offer cultural tailored, personalised care.

10.2.2. Phase 2 – Planning pilot training Intervention workshop – Content

Considering the validated GFT (*Chapter 8*), an introductory Continuous Professional Development (CPD) training package was proposed (1.5-hour content). This training package was designed to promote the transfer of psychological theory into applied clinical practice. This CPD aimed to improve health professional's understanding of patient's social-cultural identity alongside improving their communication skills towards individual person-centered patient needs.

According to the GFT and the validation study (*Chapter 9*), health professionals needed to better understand patients health beliefs relevant to their T2D. The empirical evidence suggested that SA patients have contributing factors that influence their diabetes management, the findings from this PhD also identified that health professional's knowledge of cultural and religious nuances was lacking. To overcome this, it was considered advantageous, in the first instance, for health professionals to develop an understanding of the GFT.

A pilot training intervention workshop was designed considering the GFT and the feedback from the validation and supplementary studies. The training outline was further refined via discussion and review between the research team. The aim of this intervention was not to merely teach health professionals about the GFT, but rather to find a way to help health professionals apply elements of the GFT, to aid their understanding and hence improve their applied clinical practice (in real-world patient settings). (Note* it may be beneficial to develop a comprehensive teaching module focusing entirely on the GFT as a theoretical model). Whilst theoretically-informed interventions have been shown to produce effective outcomes (Michie & Prestwich, 2010) , here in the context of feedback from the validation study, there was a need for this training intervention to offer practical support, and for the CPD to address a specific call for applied learning, as opposed to teaching health professionals about a theoretical framework. Consequently, this CPD training intervention used the GFT as a starting point to inform the overview and needs of the health professional intervention, and also used insights from the theoretical GFT and empirical research discussions (Brug, Oenema & Ferreira, 2005).

From a theoretical perspective, the higher-order constructs presented within the GFT aligned to a number of existing psychological and social theories. The GFT integrated aspects of individual behaviour change and psychological well-being. With specific reference to the GFT third order construct ‘Psychological Conflict’, the SRM of behaviour (Leventhal, Meyer & Nerenz, 1980) was relevant here, and we proposed that aspects of the GFT integrated aspects of the SRM. The SRM suggests that individuals are active problem solvers in managing their health. Individual’s self-monitor health-related experiences and symptoms and they evaluate available alternatives for responding to perceived deviation in health. This then creates a common-sense model of their health by integrating knowledge and beliefs across several illness representations. The SRM (Leventhal, Meyer & Nerenz, 1980) can be useful to understand further why individuals do not adopt recommended self-management advice, and it can explain why individuals may be experiencing psychological conflict and distress. This theory suggests that individuals start exploring ways to understand their illness by developing a sense of meaning in what the disease is, its causes, its consequences, how long it will last, and whether it can be cured or controlled. This understanding (or illness representation) is not necessarily scientifically or medically validated but formulated from personal experience (physical symptoms and emotions), which inform their illness beliefs, in turn influencing their coping strategies and evaluation of the situation. Individuals are thought to reduce their health risk or change their health behaviour in ways consistent with their illness representations (health beliefs). For patients who for example, do not believe T2D to be a severe condition; to have a short timeframe; or to be an inevitable condition (which all SA people get eventually) etc, means that their coping behaviour and evaluation of the self-management behaviours are direct responses to these (often inaccurate) health beliefs. Failure to address such health beliefs directly during health care consultations might explain SA patients poor adherence to health advice, deviation from self-management behaviours and poorer clinical outcomes (compared to Caucasian patients, Bhopal, 2013; Sattar, & Gill, 2015; Modesti et al., 2016).

The SRM (Leventhal, Meyer & Nerenz, 1980) has been widely used in the literature (Ross, Walker & MacLeod, 2004). A recent systematic review carried out by Jones, Smith and Llewellyn (2016) evaluated the effectiveness of interventions using the SRM (Leventhal, Meyer & Nerenz, 1980) to improve adherence behaviours, and this review suggests that measuring illness perceptions can improve health outcomes. In the context of diabetes, there is evidence to suggest that individual beliefs were related to better control in T2D (Oftedal, Karlsen & Bru, 2010). Watkins, Connell, Fitzgerald, Klem, Hickey and Ingersoll-Dayton (2000) found that individuals who had higher levels of diabetes knowledge and perceived control beliefs were significant predictors of higher levels of participation in self-care behaviour. Cognitive coping strategies have been found to have a positive influence in improved metabolic control (Gafvels & Wandell, 2005). Jayne and Rankin (2001) conducted a study involving 30 qualitative interviews and analysed the results were categorising into the SRM (Leventhal, Meyer & Nerenz, 1980) dimensions. Findings from this study suggested that the participants had a lack of knowledge about diabetes, and interpreted having diabetes as a stigma. A number of coping strategies were identified such as keeping the condition a secret and feel the need to avoid social situations. It was concluded, that health professionals could help patients by helping them identify strategies to cope instead of telling them what to do. A study conducted by Paddison, Alpass and Stephens (2010) examined the relationships between illness perceptions and illness-related distress, involving 615 patients with T2D who completed a questionnaire, revealed ‘making sense’ of diabetes may be central to successfully managing the emotional consequences of diabetes. The SRM (Leventhal, Meyer & Nerenz, 1980) focuses on illness beliefs which can aid behaviour change as if health professionals can tackle those illness beliefs this can lead to more of a positive outcome and a sustainable behaviour change as the patient has changed their beliefs and are working towards new goals. The SRM (Leventhal, Meyer & Nerenz, 1980) currently offers little guidance related to the design of interventions (WHO, 2003). While the theory seems intuitively appropriate, specific suggestions are needed as to how these processes could promote adherence.

While previous research has explored the use of SRM for patients with diabetes. Previous research has not considered the variable characteristics of patients, and how factors such as religion, ethnicity and social-cultural factors also influence health beliefs, coping strategies and behavioural outcomes. Here the relevance of the SRM to the PhD findings, covers the higher-order constructs related to psychological and communication processes, although the GFT highlights the need, within the context of the SA population, to add in variables associated with social and cultural understanding.

The GFT itself is a complex theoretical model, and thus one step towards promoting the GFT would be to develop aspects of the SRM further (Leventhal, Meyer & Nerenz, 1980). Aiming to help build an understanding of their patient's illness representations.

Religion, ethnicity and cultural behaviour are considered sensitive topics to discuss with patients, and health professionals are wary not to cause offence to individuals. Thus here, it is useful to adopt an individual behavioural theory to help explore psychological and communication issues associated with T2D, by exploring a patients illness representations, e.g. via

SRM. However, the GFT suggest that in addition, aspects of religion, ethnicity and social-cultural behavioural should be integrated within this approach. This would be an enhancement of the SRM theory, but using such a model would be practical and simpler to explain to health professionals than the complexity of the GFT itself. Adding in a cultural context of T2D and integrating aspects of social comparisons (external influences) on self-management behaviours advances the SRM (Leventhal, Meyer & Nerenz, 1980) model beyond that of individual psychology, but offers a starting point to promote and integrate the GFT into clinical practice (*Figure 10.1*).

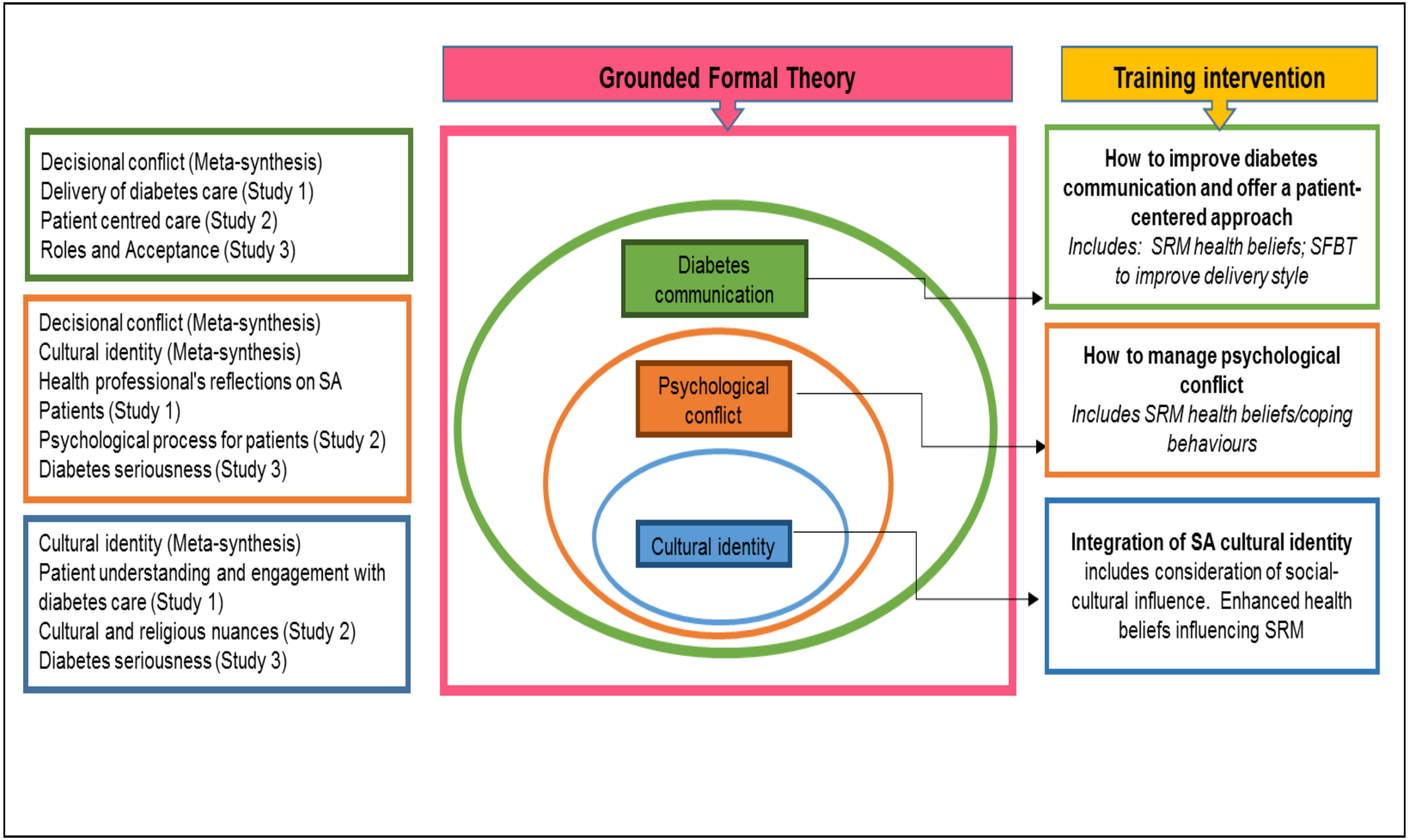

Figure 10.1: Training Intervention utilising components from GFT constructs

Implementation of the pilot training intervention programme:

Teaching Strategy

> "Learning is both affective and cognitive, and it involves identity shifts which can entail troublesome, unsafe journeys. Often students construct their own conditions of safety through the practice of mimicry… in this case, learning is the product of ritualised performances rather than integrated understandings" (Cousin, 2006, p. 5).

There are a number of theories and models that can be adopted when designing a session that involves teaching (e.g. Biggs, 1992; Lockitt, 1997; Honey & Mumford, 1986). Honey and Mumford (1986) model, suggest learning style is "…a description of the attitudes and behaviours which determine an individual's preferred way of learning" (*Table 10.2*).

Table 10.2: Learning model

Author	Learning approach	Methods used in programme
Honey & Mumford, 1986	1. *Activists:* need a range of activities to keep them interested 2. *Reflectors:* need opportunities to engage with learning and think deeply 3. *Pragmatist:* needs opportunities to try out what they have learnt 4. *Theorist:* requires time to explore links between ideas and situations	1) The training included a variety of activities, including case study, discussions, tasks 2) Opportunities to ask questions and discuss the material. Individual tasks allowed health professionals to reflect on the material 3) Case studies offered an opportunity for health professionals to explore model and techniques 4) Health professionals encouraged to think about links between information and practice

Materials: Training material was designed using Farrow's (2003) 'LIGHT' model (*Table 10.3*):

Table 10.3: LIGHT model

Links (obvious and direct links to the session)
Intelligibility (teaching material should be easy to understand and learn from)
General style (aim to use a consistent style throughout teaching materials)
Highlighting (highlighted information helps to give emphasis to important issues
Targeting (teaching targeted to needs)

The sessions were designed to be interactive, and health professionals were encouraged to get involved via group discussions and were asked to reflect throughout. The content included a PowerPoint presentation (*Appendices 10.5, 10.6, 10.7 & 10.8*) resource pack (*Appendix 10.9*) for the health professionals to use during, and after the session. This pack included a practical explanation of the SRM model (Leventhal, Meyer & Nerenz, 1980), a case study example, a blank IPQ-R (Weinman et al., 1996), diabetes-specific SFBT (Berg, 1994) questions, a copy of the Eat well guide plate (NHS choices, 2016) (Ethnic/UK adaptation), a hand portion guide, and a Ramadan assessment template (Hassanein, Al-Arouj, Hamdy, Bebakar, Jabbar, et al., 2017). Using this resource during the session created a discussion from the health professionals.

For the psychological element of the pilot training intervention programme, the SRM (Leventhal, Meyer & Nerenz, 1980) was used to understand patient behaviour (*Table 10.4*). A case study of a patient was presented as part of the pilot training intervention workshop, and this case study overlaid the concepts of the SRM (Leventhal, Meyer & Nerenz, 1980) so that health professionals could gain a realistic understanding of how using this model could be applied in practice. A copy of the Brief Illness Perception Questionnaire was also provided, and health professionals learn how patients cluster ideas about their illness. This aspect of the intervention programme encouraged health professionals to assess clients' illness perceptions, as part of psychosocial understanding (*Table 10.5 for teaching plan*).

Table 10.4: Overview of SRM illness representations

Health Beliefs – SRM (Leventhal, Meyer & Nerenz, 1980)

1. Identity refers to the label given to the illness
2. The perceived cause of the
3. Timeline refers to beliefs about how long an illness will last
4. Consequences refers to the patient's perceptions of the possible effects of the illness on his or her life
5. Curability and controllability refer to the patient's beliefs about whether their illness can be treated and cured, and the extent to which its outcome is controllable

In addition, given the need for health professionals to develop their 'skills' in personalising care towards cultural needs, Solution Focused Brief Therapy (SFBT, Berg, 1994) was deemed a practical technique that could be employed. There is evidence to suggest that SFBT (Berg, 1994) is a useful technique nurses can be trained in and integrate into practice (Bowles, Mackintosh, & Torn, 2001). SFBT (Berg, 1994) focuses on strengths rather than problems. It is a patient-centred approach as it allows patients to define their own solutions and the direction of the therapy, this is based on elements such as their strengths, past success and preferred future. Using this approach enables patients to see change through identifying what they want to be different in their lives, seeing the situation positively based on their strengths, learning they have to make a change, and experiencing success through small changes. The SFBT (Berg, 1994) techniques were added to the pilot training intervention workshop as practical but positive techniques to help improve health professional and patient interactions. SFBT (Berg, 1994) aimed to directed conversations towards developing and achieving patients' vision of solutions.

Table 10.5: Teaching Plan

Tasks	**Outcome – Improve…**	**Theory-Based Methods**	**Ideas On How To Integrate Into Practie**
10mins Discussing challenges	*Awareness*- Improve health professional's ability to assess patient needs *Knowledge* – of cultural backgrounds and barriers	Information delivery (passive learning) Information processing (active learning)	*Resource Pack* PowerPoint
15mins Talk about the SRM (Leventhal, Meyer & Nerenz, 1980) Overview SRM (Leventhal, Meyer & Nerenz, 1980) and discuss the application of SFBT	*Awareness*- Improve health professional's ability to assess patient needs *Knowledge – Self-efficacy* – Confidence to give culture-specific advice	Information delivery (passive learning) Information processing (active learning) Modelling; Health professionals explore how to incorporate models and therapy into practice Goal-setting	*Resource Pack* Solution-focused therapy IPQ SRM (Leventhal, Meyer & Nerenz, 1980) model
15 mins – 10 mins show and tell 5 mins group discussion Resource task	*Self-efficacy* – Confidence to give culture-specific advice *Skills* – Ability to recognise and work with different cultures	Self-reflection	*Resource Pack* Eat well guide plate Hand portion guide
15 mins – 10 mins discussion 5 mins to present Case study – Practical task	*Self-efficacy* – Confidence to give culture-specific advice *Skills* – Ability to recognise and work with different cultures *Attitude* – Towards cultural differences *Social influence* – Understanding of cultural commitments	Positive reinforcement Modelling; Health professionals explore how to change the delivery of care Goal-setting	*Resource Pack* PowerPoint Ramadan assessment

10.2.3. Phase 3 – Implementation

Rigorous theory testing occurs not in tightly controlled contexts, but rather in imperfect settings. (Green & Glasgow, 2006), therefore four cycles of training development took place following repeated cycles: plan; action; observe and reflect (*Figure 10.2*) to implement and refine this training (based on psychological approaches) into clinical (real-world) practice and improve service development for patient experiences.

The aims of the health professional pilot training intervention workshop were to:

1) Improve health professional-patient communication to enhance patient's self-management of diabetes and subsequent clinical outcomes.

Objectives

- Support health professionals to offer truly personalise patient-centred care to their patients, by tailoring communication via psychological applications.
- Improve health professional's confidence/ competence in supporting patients from a SA descent.

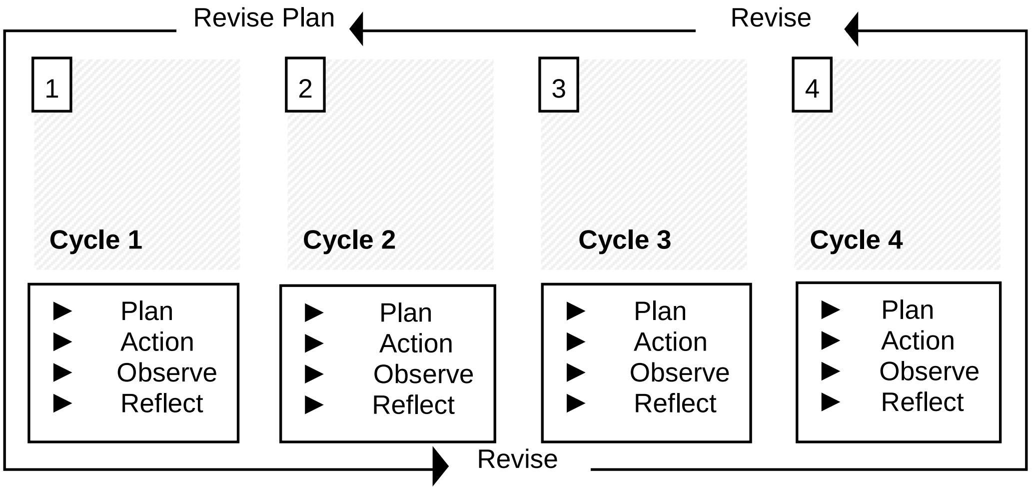

Figure 10.2: Implementation Process

Cycle 1

The first cycle of 'action' was a test phase with university Health Psychology master's students (n36). The majority of students were white Caucasian. However, three were SA. Students found the session informative although became overly concerned with understanding religious and cultural nuances (e.g. raising concerns about lack of religious knowledge) rather than focusing on the application towards patient-interactions. This over-focus detracted from the aim of the sessions in developing psychological skills. Therefore, the structure of the PowerPoint was adapted, so the focus was more to enhance aids in effective communication to overcome conflict by applying psychological models and therapies to encourage more understanding.

Cycle 2

This cycle was adapted to make it more patient centred, rather than being perceived as a religious/cultural focus. Cycle 2 was conducted with final year Nursing students (n30) who reported having received cultural awareness training and applying this to their patients during practical training. This cohort again was predominately Caucasian. As such discussing their understanding of culture and ethnicity appeared a challenge for some. The cohort again became overly focussed on religious understandings. During the session, further adaptations were made to reposition the importance of communication, and personalisation prior to integrating ethnic and cultural needs of patients.

Following this session, the implementation of the GFT was re-ordered in the training order (*Figure 10.3*).

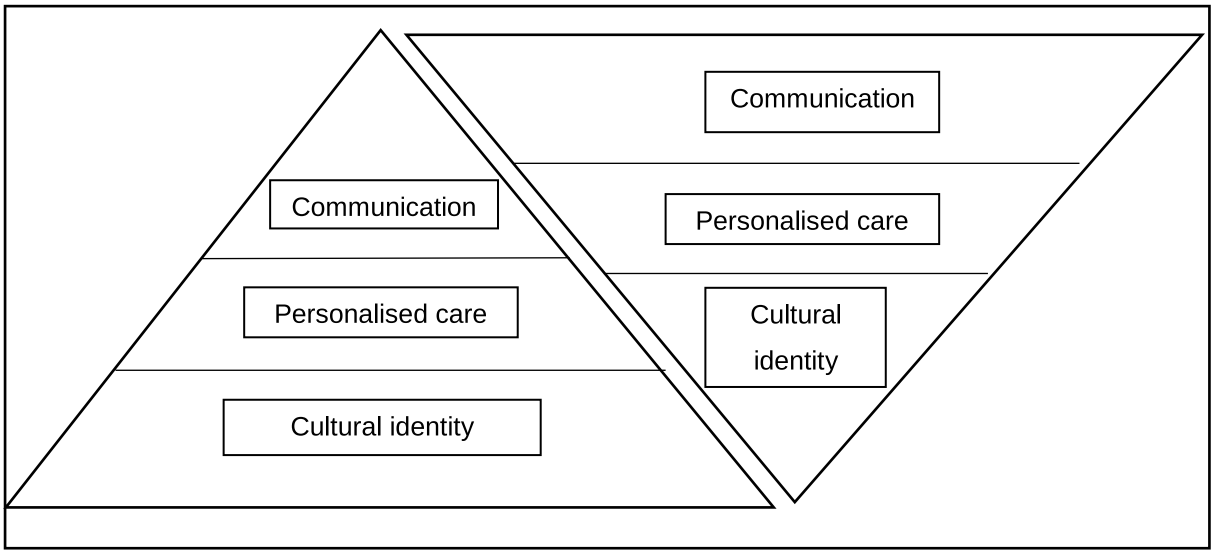

Figure 10.3: GFT re-ordered

Cycle 3

Cycle 3 was delivered to health professionals working in the NHS (Bolton), in an area of high ethnic diversity. The cohort of health professionals were predominately Caucasian. The integration of health psychology approaches to help position diabetes communication and using specific techniques to create an additional understanding of their patient’s health beliefs was particularly welcomed. Cultural and ethnic considerations were discussed after the basic psychological models had been explained, this implementation strategy worked better than as presented in cycles 1 & 2. Health professionals discussed case studies, and in addition, they shared experiences of their own patient issues which were used as part of group learning and discussions. Health professionals asked specific questions wanting clarification on how to raise issues with those from different ethnic backgrounds.

Cycle 4

This cycle was conducted in a primary care setting in Lancashire. Half of the health professionals were SA the rest were Caucasian. SA health professionals were able to reflect on their own knowledge and experiences, and these were used to guide training with the cohort. During the training, it was apparent that discussions regarding the personalisation of patient care relative to cultural issues were rarely addressed during the consultation, the training appeared to help health professionals reconsider this aspect of their role and how to personalise care taking into account cultural competency.

The final pilot training intervention workshop reflected on the feedback received during the four training cycles. The final version was subsequently amended and included case studies from discussions held during the training sessions themselves (real-world examples of patients with T2D and considerations made (or not) regarding cultural and ethnic needs, as provided by a health professional, consent to use these was sought).

10.2.4. Phase 4 - Evaluation

Evaluation is an important part of a learning process (Eseryel, 2002). The evaluation was implemented through the adoption of the Context; input; Process; Product (CIPP Model, (Stufflebeam, 1983)):

1. **C**ontext: obtaining information about the situation to decide on needs and to establish programme objectives
2. **I**nput: identifying educational strategies most likely to achieve the desired result

3. **P**rocess: assessing the implementation of the educational programme
4. **P**roduct: gathering information regarding the results of the educational intervention to interpret its worth and merit

Once the sessions were completed, evaluations took place in three ways:

A) Participant evaluation
B) Peer observation
C) Self-reflection

10.2.4.1. Participant evaluation

Evaluation occurred throughout each phase of the participatory research process to ensure the pilot training intervention workshop was adapted and filtered to meet the needs of the health professionals (context and input). Additional evaluation regarding the delivery (the process of training) was also sought throughout. All participants were given the opportunity to be open to discussion about the content and how improvements could be made. This process helped to develop a tangible final training package. An evaluation was completed by participants, which explored elements of the pilot training intervention workshop (*Appendix 10.10*).

10.2.4.2. Peer observation

Peer observation is the process of being observed by others, with the aim of improving practice (Hendry & Oliver, 2012). For this pilot training intervention workshop, DoS provided peer observation. For the observed session, I received constructive feedback which I applied to the rest of the sessions. For example, repeating responses from individuals, so that everyone had an opportunity to hear and understand point raised. Following peer observation, we discussed the issues around participants over focus with religious knowledge rather than applying cultural sensitivity towards improving person-centred care, as such the implementation plan for the following cycles were reverse so that person-centred care was presented and discussed prior to issues regarding cultural sensitivity.

10.2.4.3. Self-reflection

As the developer and trainer, a reflective report was produced highlighting the strengths and weaknesses of my (TP) experiences of training. As part of this evaluation process, I continuously sought feedback to develop my training skills (For example, as described above my DoS observed one of my sessions and provided feedback). I was able to reflect on this feedback and make changes to my approach, which I applied to the next set of sessions for this training programme. For example, acknowledging that the health professionals may not have prior knowledge of the SRM (Leventhal, Meyer & Nerenz, 1980) and SFBT (Berg, 1994), ensuring that I provided a comprehensive explanation so that they have a clear understanding of how useful the techniques are in practice.

On reflection, I think I got nervous and thought too much about delivering the content of the session; I did not think about the physical aspects of teaching, such as where I was standing. From the feedback and completing the sessions, I realised that the content and the delivery is important, but there are other aspects that need to be considered. During this training programme, I also acquired feedback from the health professionals themselves. I frequently reflected on the way I delivered my teaching sessions by writing up my thoughts after the sessions, which allowed me to develop my skills. The following are extracts of my self-reflection:

Cycle 1 - I realised that religion as a topic is a sensitive (you can easily cause offence, not that I did but became acutely mindful of how sensitive this topic can be), which can make some people hold back. During cycle 2, I decided to put a disclaimer notice on the slides to emphasise that the session was not about learning about different religions, but rather the psychological underpinnings of a patient's illness beliefs and how religious obligations can play a role. So that the session identified how health psychology could help tackle those beliefs by applying psychological models and therapies by asking questions related to their illness beliefs rather than religion itself. For the following cycle, I improved aspects of the training tasks by asking the group to discuss a real client that they have worked with and identify if it would have been useful to apply the psychological theories.

Cycle 2- This was an interesting group as it was final year nursing students, so I knew they would have had some patient interaction and some with SA patients, I was excited to have a good discussion about this topic. I quickly came to realise that some of the students had an awareness of fasting but had not considered how it could influence health beliefs or how it would have an impact on patients T2D beyond basic awareness. All the participants were unsure how to deal with a patient who had strong religious beliefs. This was a very sensitive topic to discuss; participants were unsure how to tackle those beliefs. Most participants were asking for specific solutions, how they would change their patient's beliefs. For the next cycle, I re-worded and changed the session objectives and improved the tasks by making the point that I could not give a definite solution to the issues, *but rather help them consider the evidence base (which suggests that religious beliefs play a role in diabetes management and highlighting those issues, e.g. Fasting/feasting). Then to help them learn to improve their delivery of care by implementing psychological models/theories/ techniques which could help patients to improve their self-management behaviours. Cycle 3 - On reflection, culture and religion are topics that most health professionals are apprehensive to discuss. However, applying the SRM (Leventhal, Meyer & Nerenz, 1980) and SFBT (Berg, 1994) to their practice can create a conversation that does not challenge religion, however; it does allow to identify how they perceive their illness and how it can be helped.*

For the final cycle (4), the participant sample targeted a mixed group of health professionals from primary care settings.

During this training cycle, health professionals raised concerns regarding the application of the Eat Well Guide, specifically recognising that it was not always appropriate for SA patients (there was a call for more specific dietary advice for SA patients, although this was beyond the scope of this training session). They felt that the IPQ questionnaire was a good tool to incorporate into care and suggested this could be used before a consultation or with directly with a patient, to help identify where they were at with their beliefs. The health professionals believed this would help them to tailor the advice offered. Health professionals recognised the need to develop their confidence, knowledge and skills to support SA patients with T2D.

10.3. Discussion

Through a process of continuous evaluation, this training package was adapted according to the needs and feedback of the participants working in the real world with SA patients with T2D. The intervention provided cultural-specific information and integration of psychological theory and techniques to support health professionals to understand diabetes beliefs and behaviours from the patient’s perspective, in an attempt to offer a practice-based evidence application of the GFT developed from this earlier research.

Overall, the process of participatory research was seen as beneficial; it allowed the professional to learn a new method of receiving information that could be used and implemented into practice. The health professionals appreciated the opportunity to explore challenging topics and how to overcome them in practice. Suggesting that promoting psychological models, such as an adapted SRM (Leventhal, Meyer & Nerenz, 1980) and SFBT (Berg, 1994) can allow health professionals to explore the patient's challenges by eliminating potential communication barriers. This pilot training intervention has been designed to change health professionals own clinical practice by teaching them how to implement health psychology into their daily clinical care with patients. The training itself utilised elements of the GFT and aligned closes to an adapted version of a health psychology model, the SRM (Leventhal, Meyer & Nerenz, 1980). This training programme was applied and offered practical approaches to help the health professionals become more effective in supporting their SA patients. The health professionals were provided with practical tools to implement (such as the IPQ-R (Weinman et al., 1996); SFBT (Berg, 1994) and; copies of an SA adaptation to the Eat Well Guide. During the session, the health professionals used these tools to reflect on past patient experiences regarding personalised patient care and integrate questions regarding ethnicity, religious and social-cultural relevance of the patient’s lifestyles into their interactions. Health professionals were also provided with a resource pack for future implementation.

10.4. Follow-up

To-date health professionals who engaged in the training (cycles 3 &4) have reported implementing various aspects of the training package into their practice. The IPQ has proved to be a useful tool to help the health professionals identify and explore patient’s specific health beliefs and then using these answers as a starting point towards exploring social-cultural or religious influence on health beliefs.

In addition, the practical SFBT (Berg, 1994) techniques have also been applied; health professionals found SFBT approach helped them to promote positive behaviour change rather than feeling ‘stuck’ with patient problems, this as a basic approach gave health professionals confidence and reduced their anxiety about having difficult conversations with patients. Health professionals have also reported reflecting further on their experiences and practice with patients from ethnic minority (SA) backgrounds, and this training has highlighted the need for health professionals to learn more about religious, ethnic and social-cultural influences on patient-interpretations of advice and care offered.

The final pilot training intervention included specific case studies, provided by the participants. The training itself utilised health psychology theories, asking the health professionals to use specific questions to challenge their patient's illness beliefs, coping strategies and behaviours, and to consider such beliefs in relation to personal culture and religious nuances. Previously health professionals have oversimplified ‘religious and social-cultural’ nuances (e.g. making assumptions on issues such as fasting for Ramadan). During the training, the health professionals reflected on their past experiences in tailoring care and how they responded to cultural needs during their interactions. This process has highlighted health professionals need support and guidance to assess psychological understanding of patients.

10.5. Conclusion

As stated in the previous chapter (9): “if we want more evidence-based practice, we need more practice-based evidence” (Green & Glasgow, 2006, p.126). Indeed, it is acknowledged that the GFT was a theoretical model which incorporated constructs such as cultural identity, psychological factors and diabetes understanding. However, as a result of feedback from the validation study, there was a call from participants to develop an applied and practical understanding of the GFT (participants validated the GFT although still had questions about how they could implement this new knowledge into their clinical practice). Hence the focus of this pilot training intervention aimed to focus on practical application of the GFT. This training package promoted elements of the GFT and utilised an adapted version of the SRM (Leventhal, Meyer & Nerenz, 1980) which in addition to individual health beliefs, also incorporated aspects of ethnicity, religious and social-cultural influences of behaviour. This approach provided an opportunity for health professionals working in T2D to be introduced to the key elements of the GFT and thus to fully consider psychological, communication and cultural identity issues which appear to be central to providing personalise patient-centred care to SA patients with T2D. Whilst this training intervention has been designed as an introductory CPD package (introducing concepts of the GFT to health professionals). It is noteworthy that a more comprehensive training package covering the theoretical detail of the GFT might be feasible and offered as an extended training programme (perhaps as a module on an undergraduate nursing programme, or as an accredited training package for diabetes training), although this was deemed beyond the scope of this PhD research. Moreover, the training package developed here has been designed for health professionals themselves, in response to the PhD empirical research and the GFT validation study. However, it is important to highlight that the GFT is a complex theoretical model and could also be used to develop patient, and or family member interventions and resources.

Part D

Chapter 11: Discussion

Chapter 11: Discussion

Chapter 11 - Chapter overview

This discussion summary brings together this PhD's key contributions to new knowledge. Followed by a section on research strengths and limitations (focusing on rigour in qualitative research, specifically with reference to the method, theory and researcher triangulation). Dissemination of research findings and considerations for future research are also explored.

11.1. Introduction

The role of diabetes and self-management is complicated, more specifically; the SA population have additional needs that may not necessarily be taken into account within diabetes care in the UK (Ikeda, 2004). The evidence presented in this PhD has explored cultural and religious factors which contribute and further complicate the needs of those with T2D. NICE (2015) guidelines suggest that health professionals should tailor advice to individual needs taking into account culture and beliefs. However, this research has highlighted significant issues in delivering meaningful communication and understanding the needs and beliefs of SA individuals with T2D, especially where (cultural) identity-diabetes conflict may exist.

11.2. Unique contribution

The unique contribution of this thesis includes the development of theory from multiple perspectives creating a true GFT. The studies have explored SA T2D, and this research has attempted to be inclusive and represent the diverse heterogonous nature of SA population (within the local population of the North-West), which previous studies have not considered (but have either only considered SA people as a homogenous group or have focused on individual or small subgroups of SA people). Previous research may have flagged issues around culture or religion, or indeed highlighted the need for person-centered care to be improved in T2D management. However, this PhD is the first to go beyond merely identifying factors that can influence diabetes management, and this new research suggests meaningful explanations as to why these issues may occur. Furthermore, whilst this research has created new evidence, it also goes beyond and moves the findings into practice-based evidence, by applying the GFT into a training intervention for health professionals, with the ultimate aim of changing healthcare delivery and thus has the potential to a make real-world impact and to improve T2D care, outcomes and SA patient experiences.

11.3. Key findings from this PhD

This thesis reinforces that although there is some evidence to help understand diabetes management in SA population, taking a holistic approach considering the influences of (a) health professionals, (b) the patients, and (c) their family members, when trying to understand diabetes self-management in SA. Previous studies have not used this approach, subsequently allowed to identify a gap in knowledge about health professional's delivery of care. The GFT is applied to a training intervention to encourage health professionals to apply aspects of the GFT and implement psychological theories and techniques to improve delivery of care.

The findings suggest that health professionals need to take into account cultural identity as it can influence the outcome of care. Indeed, culture and religion can be sensitive topics to address (Hordern, 2016). However, employing a tailored psychological approach, such as applying an adapted SRM (Leventhal, Meyer & Nerenz, 1980) or using SFBT (Berg, 1994), as tools to do so, can allow health professionals to target specific needs of patients. The discussions within each study emphasised how imperative it is for health professionals to explore and support the psychological understanding and needs of individuals with T2D.

This research applied a sound methodology, justification for approaches, decisions and explanations. A robust analysis was adopted throughout ensuring the quality of this research. The individual research studies present unique contributions to research knowledge and explore specific study aims. However, the triangulated approaches adopted throughout this PhD thesis offered a genuinely integrated and holistic analysis to answer the overarching PhD aim of exploring self-management behaviours in the UK SA population with T2D.

11.4. Research strengths and Limitations

11.4.1. Establishing rigour within qualitative research

Triangulation: This PhD adopted a qualitative approach, it was therefore essential to ensure rigour by implementing triangulation techniques (Munafò & Smith, 2018) throughout the research.

Although discussed in Chapter 4, and specific methodological considerations have been described in the study chapters, this section emphasises how triangulation was adopted throughout the PhD as a whole and how it helped to develop a reliable and applicable GFT.

Triangulation refers to the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena (Patton, 1999). Triangulation also has been viewed as a qualitative research strategy to test validity through the convergence of information from different sources. Denzin (1978) and Patton (1999) identified four types of triangulation: (a) method triangulation, (b) investigator triangulation, (c) theory triangulation, and (d) data source triangulation and the following commentary considers these triangulation types and describes how these elements have been achieved.

11.4.2. Method Triangulation

Methodological rigour and credibility were ensured throughout by presenting clear aims and objectives for each study and the PhD overall (*For example see meta-synthesis (Chapter 3); study 1 (Chapter 5), study 2 (Chapter 6), study 3, (Chapter 7), study 5, (Chapter 10*)). Moreover, clear justification for the chosen research methodologies and analysis was provided (*Chapters 3-7*). Upon the commencement of this research, the researcher presented an indication of the epistemological and theoretical stance of the PhD (*Chapter 4*) and reflected on this throughout.

The trustworthiness of this qualitative research was ensured through a variety of methods and approaches: Recruitment procedures, sampling methods and participant characteristics were reported for each study, representing a sample relevant to each research question. Data collection and analytical processes were described (and recorded), with explicit acknowledgement of simultaneous data collection and analysis conducted to reach theoretical development and saturation (according to GT, Strauss & Corbin, 1990). The analysis was coded and systematically recorded (audit trail), with reflections and interpretations acknowledged (internal validation) (*For example see appendix 11.1 for samples of such documentation*).

Qualitative researcher bias carefully considered throughout the PhD process. Attempts to mitigate researcher bias occurred through various methods. For example, analytical interpretations of data were challenged through discussions within the multi-ethnic research team (*mixed ethnicity and mixed researcher experience, as described in chapter 4, pages 131-136 – sub section 4.8*). Researcher reflection occurred during and after each study. To ensure findings represented the perspectives of the participants, rather than the interpretation of the researcher, a selection of verbatim quotations from a range of participants was included in each results section to support analytical commentary. Throughout this research, we (the research team) remained sensitive to context and transparent (Yardley, 2000).

11.4.3. Theory triangulation

Theoretical triangulation was evident through the development of GT frameworks presented in each study. The findings of each study subsequently informed the next stage and the overall direction of this PhD[2]. These GT frameworks were informed by theoretical and evidence-based discussions entwining the findings within and enhancing this new evidence through theoretical explanations. Previous GT research has been criticised for not being fully comprehensive as most studies report to adopt a full GT methodology, but it is more 'Grounded Theory lite' aligned to thematic analysis (Pidgeon & Henwood, 1997). A grounded theory-lite has been described as employing GT methodology

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[2]. note* the original PhD proposal assumed that the research would lead towards the development of a patient intervention and as such the PhD plan included the development of a patient intervention. Hwoever as the studies were analysed and the PhD progressed, it was apparent that there was an initial need to work directly with health professionals as a first application of the GFT, and the PhD research was adapted in occcurance with these findings.

approaches of categories to explain the relationships of the categories (Pidgeon & Henwood, 1997). However, this PhD research has taken every effort to fully conduct substantive GT research, and each study has applied GT processes and analytical procedures to produce a fully comprehensive GT framework which is substantive in targeting specific groups (Glaser & Strauss, 1987). The comprehensive conceptualisation of the GT frameworks PhD includes the meta-synthesis (*Chapter 3*), and the three qualitative studies (conducted on health professionals, patients and family members; *Chapters 5-7*). These GT frameworks are transferable and could be utilised in applied clinical practice, or within broader health contexts (e.g. diabetes care more generally beyond SA population, or the frameworks might apply to other health conditions (e.g. heart disease) with SA patient groups). The final GFT merged and integrated the findings of these previous individual GT frameworks, to develop a high-order understanding of the overall PhD aim: ‘Exploring factors towards diabetes self-management behaviours in the SA population with T2D'. The strength of developing and applying a GFT (Eaves, 2001; Finfgeld, 1999; Glaser & Strauss, 1987; Kearney, 2001) as opposed to simply conducting three empirical studies and trying to summarise the findings individually, ensured quality in methods, and trustworthiness of the total evidence presented. The GFT was supported through a validation study (*Chapter 9*), which involved discussions with key stakeholders (more health professionals and patients) to explore the relevance and application of the GFT into real-world T2D practice. This validation study acted as part of the GFT quality process and again builds on the theoretical triangulation.

11.4.4. Investigator triangulation

Investigator triangulation was adopted throughout this PhD, with input sought (when appropriate) from the PhD supervisory team (or other). From the start of this PhD, it was acknowledged that the researcher was from a SA background, and had various family members living with T2D. This could have created researcher bias related to SA healthcare experiences and knowledge surrounding T2D. Having an ethnically diverse supervisory team (white and black, British, female and male) helped to ensure a reduction in such bias. For example, when coding the data and deriving the frameworks, DoS (white female researcher) was part of this process to promote deeper understanding and encourage reflection. This process of reflection and further interpretation required a high degree of qualitative research skill although promoted comprehensive, systematic and meaningful analysis.

Methodological limitations within this PhD are acknowledged, but attempts have been made to mitigate these. Study 1 involving health professionals (*Chapter 5*) was the first empirical study completed, and as a researcher, it was important to acknowledge personal researcher limitations such as lack of confidence in conducting the interviews. However, over time this was mitigated by an improvement in interviewing skill, self-reflection, and discussion with DoS regarding interviewing skills, and researcher reflection. It is noteworthy that for this study an initial analysis was conducted prior to commencing study 2 (*Chapter 7*), with patients (which informed study 2 aims and objectives). However, to ensure rigour and trustworthiness of analysis, study 1 (*Chapter 6*) findings were revisited at a later date (*once I the PhD researcher had grown in skill and confidence*) to ensure the data was theoretically saturated and to add further depth to the interpretative theoretical discussions. A similar process of quality checking was applied to the meta-synthesis analysis and discussion to ensure the second-order constructs were saturated. In addition, Study 3 (*Chapter 8*) focused on participants who were family members of those with T2D, and as such recruitment for this study employed a direct sampling methodology seeking referral and consent from (patient) participants from Study 2 (patient study, *Chapter 7*). Thus, the sample size in study 3 was limited to those participants who offered family members contact details and the referred family member consenting to participate. Thus, in this study, it is proposed that during analysis, data saturation occurred and was applied to create a theoretical framework, although acknowledged that theoretical saturation (Strauss & Corbin, 1998) was unlikely to have been achieved (as applied to meta-synthesis, studies 1 and 2 (*Chapters 3, 5, 6*)). Participant recruitment across all empirical studies was slow, and a lot of time and effort was required to promote and engage participants in the studies. This research deemed to represent local SA population, although as explained in the introduction chapter (*Chapter 1*) the SA population are a diverse, heterogeneous group, and the research focused specifically on the SA groups living in the North-West of England. The sample did not include an exhaustive inclusion of all SA sub-groups, e.g. Sri Lankan participants. Hence caution is required in interpreting the findings beyond the SA sample as it may not be representative of their views, or indeed the views of SA outside North-West England or the UK.

11.5. Implications for practice

The NHS is divided into primary care, secondary care, and tertiary care. Primary health care is the first point of contact for health care for most people. It is mainly provided by GPs, although community pharmacists, opticians and dentists are also primary health care providers. For example, most of the issues emerging in study 1 (Chapter 5) and study 2 (Chapter 6) related to primary care delivery. The development of the pilot intervention could be standardised and rolled out as a training tool for health professionals to adapt in their current services and have further involvement of psychology to help develop and design new services. Overall, this PhD thesis has contributed to clinical practice in developing health professional communication to ensure personalised patient-centered care can be achieved.

11.6. Dissemination of research findings

The research has the potential to be published in peer-reviewed journals. The studies have to date been presented at a number of academic conferences, including Liverpool John Moores University Research Day, 2014 and at applied professional conferences, such as Diabetes UK, 2017 and European Health Psychology Society and British Psychology Society, 2016 (*Appendix 11.2 for conference abstracts*). It is noteworthy that in March 2018 this research was presented at Diabetes UK 2018 for 2 sessions as an invited speaker (*Appendix 11.3*). This PhD presented applied research, and as such is relevant and applicable to health professionals working in diabetes care, allowing them to understand the psychological phenomena of what patients are dealing with. Further disseminated of the findings have been communicated (verbal presentation and summary reports) to health professionals across the areas where this research was conducted.

11.7. Recommendations for further research

Findings from study 1 (*Chapter 5*) suggest a need for further research to explore how health professionals' attitudes towards SA patients vary across different parts of the country with larger, more varied SA sub-groups. This is important given that this research was conducted in the North-West, and hence may not generalise to other areas.

This research could be extended beyond that of a health professional training intervention and evaluated fully in a clinical setting. A randomised controlled trial could be implemented to test how health professionals engage with the pilot training intervention workshop and how this changes healthcare practice and subsequent health care behaviours and clinical outcomes in SA patients with T2D (assessing self- regulatory changes, communication perceptions, management of identity conflict, e.g. comparing enhanced T2D patient education vs standard care).

Moreover, this research suggests the need to consider the role of family members in supporting the person with T2D (this may be via direct involvement in a face-to-face intervention or through the development of additional resources such as digital information, practical resources, and a peer-support group). As mentioned in study 3 (*Chapter 7*), family members own psychological wellbeing can be affected by T2D diagnosis in others (Fisher et al., 2002; Rosa et al., 2007; White et al., 2007). However, this aspect was not investigated within this PhD research, but further exploration and research with family members may indeed provide insight into family members own psychological wellbeing, which may also influence T2D management, and highlight additional needs of how to offer a more collaborative approach to T2D care.

This research has the potential for a post-doctoral project whereby the findings of this research could be intervention mapped into an intervention programme, and a pre-post-test Randomised Control Trial could establish changes in clinical outcomes.

11.8. Conclusion

The overall findings of this thesis suggest that diabetes self-management in SA is influenced by health professionals, the patient, and their families, necessitating a holistic approach to understanding self-management in the SA community. The contribution to new knowledge of this thesis suggests that delivery of care should be communicated (assessing individuals psychological and identity-based needs) to the needs of the individual thus ensuring person-centered care is achieved. Although NICE (2017) guidelines suggest a collaborative exchange between the health professional and patient with T2D, the findings from this thesis indicate that this does not always occur, especially for SA patients. Applying the GFT presented within this PhD thesis is a starting point to help with effective communication to improve T2D self-management in the SA population.

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